UNSW SYDNEY

Discovering the Interwoven Health Inequities in Aboriginal and Torres Strait Islander Children with an Acute Burns Injury

Author:
Ryder, Courtney

Publication Date:
2021

DOI:
https://doi.org/10.26190/unsworks/22346

License:
https://creativecommons.org/licenses/by-nc-nd/3.0/au/
Link to license to see what you are allowed to do with this resource.

Downloaded from http://hdl.handle.net/1959.4/70636 in https://unsworks.unsw.edu.au on 2024-03-29

Discovering the Interwoven Health Inequities in Aboriginal and Torres Strait Islander Children with an Acute Burns Injury

Courtney Ryder

A thesis in fulfilment of the requirements for the degree of

Doctor of Philosophy

The George Institute for Global Health

Faculty of Medicine

University of New South Wales

July, 2020

Thesis Title and Abstract sheet

Thesis submission for the degree of Doctor of Philosophy

Thesis Title and Abstract | Declarations | Inclusion of Publications Statement | Corrected Thesis and Responses

Thesis Title

Discovering the Interwoven Health Inequities in Aboriginal and Torres Strait Islander Children with an Acute Burns Injury

Thesis Abstract

Background
In Australia Aboriginal and Torres Strait Islander children have a greater burden of burn injuries than other Australian children. Yet to date, no research has examined this from an Indigenous perspective. This is the first thesis to use Indigenous research methodologies to provide a detailed examination of how health inequities impact on Aboriginal and Torres Strait Islander children with an acute burn injury.

Methods
The research comprised a systematic review of international injury literature, two epidemiological studies on Burns Registry of Australia and New Zealand data, a quantitative study with Aboriginal families and psychometric assessment of a survey. Indigenous knowledges and research methods were woven with quantitative research methods through knowledge interface methodology for studies.

Results
Inequities in injury burden are greatest in children from low socio-economic status backgrounds and those who experience longer hospital length of stay (LOS). Aboriginal and Torres Strait Islander children have a hospital LOS 4 days longer than other Australian children for acute burns. Remoteness, flame burns, percentage total body surface area are contributing factors. These health inequities, low socio-economic status and *Streptococcus sp.* infection are greater in Aboriginal and Torres Strait Islander children than other Australian children. While knowledge interface methodology acted to decolonise outcomes, there were limitations in data from the data source, a Western epidemiological data repository and its employed classification codes.

The manifestation of these inequities creates additional burden through Out-of-Pocket Healthcare Expenditure (OOPHE) on Aboriginal and Torres Strait Islander families. Travel, accommodation and medication are all OOPHE costs impacting families for their child's burns treatment. Financial stain was reported through inability to pay bills and social isolation. The modification of a pre-existing OOPHE survey was found to be impracticable for families.

Conclusion
This thesis describes the health inequity impacts on Aboriginal and Torres Strait Islander children with an acute burn injury through an Indigenous perspective. Engagement with Indigenous research methodologies exposed the invisible white possessive logic ingrained in burns quantitative research. Change is needed to shift this paradigm and work towards an agenda of Indigenous data sovereignty and more accurate understandings of burn injury burden.

Copyright and Authenticity Statements

Thesis submission for the degree of Doctor of Philosophy

Thesis Title and Abstract | **Declarations** | Inclusion of Publications Statement | Corrected Thesis and Responses

ORIGINALITY STATEMENT

☑ I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at UNSW or any other educational institution, except where due acknowledgement is made in the thesis. Any contribution made to the research by others, with whom I have worked at UNSW or elsewhere, is explicitly acknowledged in the thesis. I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that assistance from others in the project's design and conception or in style, presentation and linguistic expression is acknowledged.

COPYRIGHT STATEMENT

☑ I hereby grant the University of New South Wales or its agents a non-exclusive licence to archive and to make available (including to members of the public) my thesis or dissertation in whole or part in the University libraries in all forms of media, now or here after known. I acknowledge that I retain all intellectual property rights which subsist in my thesis or dissertation, such as copyright and patent rights, subject to applicable law. I also retain the right to use all or part of my thesis or dissertation in future works (such as articles or books).

For any substantial portions of copyright material used in this thesis, written permission for use has been obtained, or the copyright material is removed from the final public version of the thesis.

AUTHENTICITY STATEMENT

☑ I certify that the Library deposit digital copy is a direct equivalent of the final officially approved version of my thesis.

Inclusion of Publications Statement

Thesis submission for the degree of Doctor of Philosophy

Thesis Title and Abstract | Declarations | **Inclusion of Publications Statement** | Corrected Thesis and Responses

UNSW is supportive of candidates publishing their research results during their candidature as detailed in the UNSW Thesis Examination Procedure.

Publications can be used in the candidate's thesis in lieu of a Chapter provided:

- The candidate contributed **greater than 50%** of the content in the publication and are the "primary author", i.e. they were responsible primarily for the planning, execution and preparation of the work for publication.
- The candidate has obtained approval to include the publication in their thesis in lieu of a Chapter from their Supervisor and Postgraduate Coordinator.
- The publication is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in the thesis.

☑ The candidate has declared that **their thesis has publications - either published or submitted for publication - incorporated into it in lieu of a Chapter/s. Details of these publications are provided below.**.

Publication Details #1

Full Title:	Equity in functional and health related quality of life outcomes following injury in children - a systematic review
Authors:	Ryder, C., Mackean, T., Hunter, K., Williams, H., Clapham, K., Holland A.J.A., and Ivers, R.,
Journal or Book Name:	Critical Public Health
Volume/Page Numbers:	30(3):352-366
Date Accepted/Published:	7 February 2019
Status:	published
The Candidate's Contribution to the Work:	Ryder conceptualised the systematic review design, conducted database searches, analysed and interpreted outcomes and constructed the manuscript and all changes until published.
Location of the work in the thesis and/or how the work is incorporated in the thesis:	The manuscript is located in Chapter 2 after the Chapter 2 preamble. The manuscript is included in it's full form and is the systematic review used to inform how health inequity is included and contextulised in injury research.

Publication Details #2

Full Title:	Indigenous research methodology – weaving a research interface
Authors:	Ryder, C., Mackean, T., Coombs, J., Williams, H., Hunter, K., Holland A.J.A., and Ivers, R.,
Journal or Book Name:	International Journal of Social Research Methodology
Volume/Page Numbers:	23(3):255-267
Date Accepted/Published:	16 September 2019
Status:	published
The Candidate's Contribution to the Work:	Ryder conceptualised the weaving methodology and examples provided in this manuscript. Ryder also prepared the first draft, and subsequent revisions until publication.
Location of the work in the thesis and/or how the work is incorporated in the thesis:	The manuscript is located in Chapter 3 Part B after the Chapter 3 Part A Foundations.The manuscript is included in it's full form as published and is the weaving methodology used this chapters 2, 4, 5, and 7 of this thesis.

Publication Details #3

Full Title:	Burn Injuries in Hospitalised Australian Children - An Epidemiological Profile
Authors:	Ryder, C., Mackean, T., Hunter, K., Rogers, K., Holland A.J.A., and Ivers, R.,
Journal or Book Name:	Journal of Burns Care and Research
Volume/Page Numbers:	
Date Accepted/Published:	
Status:	submitted
The Candidate's Contribution to the Work:	Ryder conceptualised the study, applied for ethics and Burns Registry of Australia and New Zealand Data, analysed and interpreted outcomes and constructed all manuscripts.
Location of the work in the thesis and/or how the work is incorporated in the thesis:	The manuscript is located in Chapter 4 after the Chapter 4 preamble. The last revised manuscript after reviewer feedback sent to the journal is included. This is the second study of this thesis investigating the epidemiological profile of burns injury in Aboriginal and Torres Strait Islander children.

Publication Details #4

Full Title:	Factors Contributing to Longer Length of Stay in Aboriginal and Torres Strait Islander Children Hospitalised for Burn Injury
Authors:	Ryder, C., Mackean, T., Hunter, K., Towers, K., Rogers, K., Holland A.J.A., and Ivers, R.,
Journal or Book Name:	Journal of Injury Epidemiology
Volume/Page Numbers:	
Date Accepted/Published:	
Status:	submitted
The Candidate's Contribution to the Work:	Ryder conceptualised the study, applied for ethics and Burns Registry of Australia and New Zealand Data, analysed and interpreted outcomes and constructed all manuscripts.
Location of the work in the thesis and/or how the work is incorporated in the thesis:	The manuscript is located in Chapter 5 after the Chapter 5 preamble. The last revised manuscript after reviewer feedback sent to the journal is included. This is the third study of this thesis investigating prognostic factors which contribute to longer hospital length of stay for Aboriginal and Torres Strait Islander children.

Publication Details #5

Full Title:	Yarning Up About Out-of-Pocket Healthcare Expenditure in Burns with Aboriginal Families
Authors:	Ryder, C., Mackean, T., Coombs, J., Hunter, K., Holland A.J.A., and Ivers, R.,
Journal or Book Name:	Medical Journal of Australia
Volume/Page Numbers:	
Date Accepted/Published:	
Status:	submitted
The Candidate's Contribution to the Work:	Ryder conceptualised the study, applied for jurisdictional ethics (9 HRECs), conducted the field research (yarning sessions), analysed and interpreted outcomes and constructed the manuscript.
Location of the work in the thesis and/or how the work is incorporated in the thesis:	The manuscript is located in Chapter 6 after the Chapter 6 preamble. The original manuscript form submitted to the journal is included. This is the fourth study of this thesis and the only qualitative study included in this thesis. The study focus was on scoping out-of-pocket healthcare expenditure with Aboriginal families whose child had sustained a severe burn inury. The outcomes from this study are used to inform the final study in Chapter 7 of this thesis.

Candidate's Declaration

I confirm that where I have used a publication in lieu of a chapter, the listed publication(s) above meet(s) the requirements to be included in the thesis. I also declare that I have complied with the Thesis Examination Procedure.

Acknowledgements

Acknowledgement of Country

Always Was Always Will Be

This thesis must start by acknowledging the traditional owners of the lands that it was conducted on. I would like to respectfully acknowledge and pay my respects to Elders past, present and emerging across the lands of the Kaurna and Eora Nations and recognise their continuing connection to land, waters and culture.

I would also like to acknowledge all the Aboriginal mentors, colleagues and participants who were part of this journey. Your stories and guidance are very much grounded in this thesis, for that I will always be truly grateful.

Acknowledgements of People & Organisations

When thinking about this thesis, from end to completion I was drawn to reflect on a meme, that eating an elephant can only be done in one way: one bite at a time. Throughout my PhD journey I would often joke I was eating my PhD elephant. On reflection however, I'm not too sure this is the best way to eat an elephant, this way would be lonely and isolating. Instead I suggest that the most practical and fun way to eat an elephant, is with a range of people, who are like-minded, a collective community of PhD elephant devourers, or connoisseurs. After all, surely it takes a whole village to eat an elephant!!

With this in mind I must start by acknowledging and thanking my connoisseurs, being my amazing supervisory panel. Firstly, Professor Rebecca Ivers, I'm not too sure you realised what you were getting yourself into when I interviewed you to be my primary supervisor but thank you. Thank you for your guidance, support and belief in me over this journey, especially in those early days when I doubted myself so much, you provided me with the mentoring I needed to realise I had so much to give. Secondly, Associate Professor Tamara Mackean, from the days our paths first crossed so many moons ago, I always knew you would supervise my PhD. Words cannot even begin to describe how much you have done for me both personally and professionally. I am very fortunate to be mentored by such a strong and amazing individual, your friendship is a gift that I treasure. Thirdly, Professor Andrew Holland, thank you for your guidance, support and clinical perspectives, also your quick turn around on feedback!! Fourthly, Dr Kate Hunter your kind, caring passionate nature and support is what every PhD student needs, especially when learning multiple statistical platforms!

To the National Health and Medical Research Council, thank you for your postgraduate scholarship award (APP1133121) to allow me to do my PhD. Thank you to the chief investigators and associated investigators involved with the Coolamon study. Particularly my PhD tiddas who were part of this journey, Dr Sarah Fraser, Julieann Coombes and Hayley Williams. Special thanks to the co-authors involved in my studies and manuscripts, especially Associate Professor Kris Rogers. Your statistical expertise, empathy and humour were appreciated throughout.

Thank you to my employers Flinders University, who provided me with the study leave and space on campus to do this work. To my work colleagues in Aboriginal and Torres Strait Islander Public Health, thank you for your ongoing encouragement. In particularly Roland Wilson and Emma George for our morning coffee ritual and debrief, which was probably more or less me whinging about my PhD! Professor Neil Piller, thank you for your encouragement and your many hours of proof reading over various parts of my work. Thank you to my best friend Liz, who I am sure got tired of hearing about my PhD, you have and always will be a huge support. Thanks to my colleagues and fellow PhD students at the George Institute for Global Health, especially the Aboriginal and Torres Strait Islander program manager Keziah Bennett-Brook.

To the Elders, family and friends who were present at the start of my journey, but unfortunately did not see the completion thank you, you are dearly missed by all. Dr Kathryn Browne-Yung, your contribution, words of wisdom and encouragement to this thesis will always be remembered, yarns which I will continue to miss.

Lastly, I want to thank my family. My Mum Shirley and Dad Warwick, a big first for our family! Thank you for your love, support, encouragement and child minding during this time. Ditto to my mother-in-law Di especially all the chocolate you supplied! To my husband Shaun, you know how important this work is to me, you absolutely get it. You whole heartedly encouraged me to start this journey, you have done nothing but support me to get through. I know you will always support my work in Aboriginal and Torres Strait Islander health. My daughters Charli and Isla, this thesis is dedicated to you. Always be proud of who you are, may you be able to reach for stars and follow a path to do or be whatever you want.

Abbreviations

ACCHO	Aboriginal Community Controlled Health Organisation
ABI	Acute Burn Injury
AHW	Aboriginal Healthcare Worker
AHP	Aboriginal Health Practitioner
ALO	Aboriginal Liaison Officer
ARIA	Accessibility and Remoteness Index of Australia
BRANZ	Burns Registry of Australia and New Zealand
CI	Confidence Interval
CVI	Content Validity Index
ED	Emergency Department
EFA	Exploratory Factor Analyses
HRQoL	Health Related Quality of Life
ICC	Interclass Correlation Coefficient
ICD10-AM	International Statistical Classification of Diseases and Related Problems
I-CVI	Item-level Content Validity Index
KMO	Kaiser-Meyer-Olkin
LOS	Length of Stay
MBS	Medical Benefits Scheme
NACCHO	National Aboriginal Community Controlled Health Organisation
%BSA	Percentage Body Surface Area
%TBSA	Percentage Total Body Surface Area
OOPHE	Out-of-pocket healthcare expenditure
OT	Occupational Therapy
PATS	Patient Assisted Travel Scheme
PBS	Pharmaceutical Benefit Scheme
PROGRESS-Plus	Place/residence, race/ethnicity, occupation, gender, religion, education, social-capital, socio-economic position, age, disability, sexual orientation, other vulnerable groups
RA	Remote Area

RTI	Research Triangle Institute
SES	Socio-economic Status
SEIFA	Socio-Economic Indexes for Area
TBI	Traumatic Brain Injury
VABS	Vineland Adaptive Behavior Scale
WHO	World Health Organisation
UN	United Nations

List of Tables Page

Table 1: Example of five commonly reported Social Determinants of Health. 24
Table 2: Some examples of multiple determinants of Indigenous Health commonly discussed in research with Aboriginal and Torres Strait Islander health. 29
Table 3: Search Terms and Databases. 46
Table 4: Selection Criteria for Articles. 47
Table 5: Equity Lens – questions developed from Nasser et al 2013 [182]. 48
Table 6: Summary of findings: studies post-injury functioning and HRQoL, with equity in children ⩽ 16 years. 52
Table 7: Learning to Basket Weave 72
Table 8: Concepts in the process of weaving a methodology. 74
Table 9: Examples of Indigenous Research Methods Used as Coiled Stitch Textiles for Weaving a Methodology for 'Research at the Interface'. 74
Table 10: Quantitative research methods/processes used in studies for chapters (2,4,5,7). . 89
Table 11: Profile of Missing Data 102
Table 12: Demographic profile of Australian children admitted to a BRANZ reporting hospital (2009-2018). 104
Table 13: Burns Injury Characteristics of Australian children admitted to a BRANZ reporting hospital (2009-2018). 105
Table 14: Burns Cause by Residential Location (ARIA) for Australian children admitted to a BRANZ reporting hospital (2009-2018). 105
Table 15: Burn Cause by Residential Location (ARIA) for Australian children admitted to a BRANZ reporting hospital (2009-2018). 106
Table 16: Stratified univariate analysis for Staphylococcus sp. and Streptococcus sp. Infection (relative to no infection) 107
Table 17: Multivariate risk ratio (RR) is infection by bacterial species (relative to no infection) in Australian children admitted to a BRANZ reporting hospital (2009-2018). 108
Table 18: Patient characteristics table 125
Table 19: Discharge ratio to Patient Demographics 127
Table 20: Discharge ratio to Injury Cause 128
Table 21: Discharge ratio to Injury Severity 128
Table 22: Discharge ratio to Treatment 129
Table 23: Human Research Ethics Approval for Scoping Study by Jurisdiction 141
Table 24: Themes and Sub Themes of OOPHE in Aboriginal families whose child has sustained a burns injury. 142
Table 25: Human Research Ethics Approval for Pilot Study by Jurisdiction. 160
Table 26: Parent Demographics from Test 1 (n = 67) 161
Table 27: Exploratory Factor Analyses and Internal Consistency of OOPHE survey (n=67, Items = 62) 162
Table 28: Test retest reliability of OOPHE survey (n=47) 163

List of Figures

Page

Figure 1: The child injury mountain (or pyramid) [15, 16, 18, 19]. Artist: Charli Ryder, aged 5. 17
Figure 2: Distribution of child mortality from burns globally in 2013, Image source: Sengoelge 2017 [28(p. 116)] 18
Figure 3: The social determinants of health, image from Dahlgren and Whitehead 1991 [90(p. 11)]. 23
Figure 4: The Balance of Health and Well-being. For an Aboriginal and Torres Strait Islander individual, health and well-being is a balance between the dimensions of life, which are all interrelated (see The Dance of Life). These dimensions, both individually and collectively, are impacted by protective and risk factors from the Multiple Determinants of Indigenous Health [110, 116, 117]. This process is dynamic in nature, forever-changing; it is not static or linear, reflecting that health and well-being of an individual is dynamic and not merely the absence of disease of infirmity. 27
Figure 5: The Dance of Life, by Professor Helen Milroy. Reprinted and described with permission from Professor Milroy [116, 117]. 30
Figure 6: Dimensions of The Dance of Life (painting title underneath image), by Professor Helen Milroy. Reprinted and described with permission from Professor Milroy [116, 117]. 30
Figure 7: PRISMA flow diagram, PRISMA-E 2012 [3]. 49
Figure 8: Weaving a research interface, weaving my research interface 73
Figure 9: Coiled Stitch Basket by Courtney Ryder. 80
Figure 10: Coiled stitch process for part of a basket, highlighting coiled stitch textiles for creating the interface 81
Figure 11: The process of research yarning, as described by Bessarab and Ng'andu [2(p. 40)] 85
Figure 12: Visual representation of research at this knowledge interface Chapter 4. 94
Figure 13: Risk ratio of staphylococcus sp. and streptococcus sp. infection for Aboriginal and Torres Strait Islander children and other Australian children. 108
Figure 14: Visual representation of research at this knowledge interface Chapter 6. 114
Figure 15: Kaplan-Meier estimates for hospital discharge across both child groups. 126
Figure 16: Visual representation for research at this knowledge interface. 151
Figure 17: Process of psychometric assessment undertaken for modification of the OOPHE questionnaire. 157
Figure 18: Scree Plot of eigenvalues after EFA 161

List of Publications

Published

Ryder, C., Mackean, T., Hunter, K., Williams, H., Clapham, K., Holland A.J.A., and Ivers, R., Equity in functional and health related quality of life outcomes following injury in children - a systematic review. Critical Public Health. 2019;30(3):352-366.

Ryder, C., Mackean, T., Coombs, J., Williams, H., Hunter, K., Holland A.J.A., and Ivers, R., Indigenous research methodology – weaving a research interface. International Journal of Social Research Methodology. 2020;23(3):255-267.

Ryder, C., Mackean, T., Hunter, K., Rogers, K., Holland A.J.A., and Ivers, R., Burn Injuries in Hospitalised Australian Children - An Epidemiological Profile. Journal of Burns Care and Research. 2020. (Epub ahead of print).

Ryder, C., Mackean, T., Hunter, K., Towers, K., Rogers, K., Holland A.J.A., and Ivers, R., Factors Contributing to Longer Length of Stay in Aboriginal and Torres Strait Islander Children Hospitalised for Burn Injury. Journal of Injury Epidemiology. 2020. 7(52).

Ryder, C., Mackean, T., Coombs, J., Hunter, K., Holland A.J.A., and Ivers, R., Yarning Up About Out-of-Pocket Healthcare Expenditure in Burns with Aboriginal Families. Australian and New Zealand Journal of Public Health (Accepted).

Ryder, C., Mackean, T., Coombs, J., Hunter, K., Ullah, S., Rogers, K., Essue, B., Holland A.J.A., and Ivers, R., Developing Economic Measures for Aboriginal and Torres Strait Islander Families on Out-of-Pocket Healthcare Expenditure. Australian Healthcare Review (Accepted).

List of Congress Papers

Key Notes

Ryder, C., August 2018, The Coolamon Journey – Burns Outcomes in Aboriginal and Torres Strait Islander Children, Women's and Children's Hospital Grand Round, Adelaide, Australia.

Ryder, C. August 2017, The George Institute for Global Health, Australian Medical Student Association Global Health Council, Adelaide, Australia.

Presentations

Ryder, C., November 2019. Yarning Up About Out of Pocket Healthcare Expenditure in Burns with Aboriginal Families. Emerging Leaders Showcase, College of Medicine and Public Health, Flinders University. Adelaide.

Ryder, C., Mackean, T., Hunter, K., Moller, H., Gabbe, B., Holland, A., and Ivers, R., October 2018, Burden of burns in Australian children. ANZBA. Brisbane. Australia. Presenter: Ryder.

Holland, A., Mackean, T., Ivers, R., Hunter, K., Kimble, R., Clapham, K., Coombes, J., and Ryder, C., October 2017, Cause and treatment of burn injuries in Aboriginal and Torres Strait Islander children: baseline data from a prospective study. ANZBA. Adelaide. Australia. Presenters: Holland & Ryder.

Posters

Ryder, C., Mackean, T., Hunter, K., Rogers, K., Gabbe, G., Holland, A., and Ivers, R., October 2019. Inequities in Burns Injuries for Aboriginal and Torres Strait Islander Children. ANZBA. Hobart.

Ryder, C. Mackean, T. Hunter, K. Holland, A. J. Ivers, R. (2018). PW 1756 Outcomes following injury in young people. 24(Suppl 2), p A181.

Grants and Awards

Ryder, C. 2019. Aboriginal and Torres Strait Islander Health Program Capacity Building Grant, The George Institute for Global Health, ($3,800).

Ryder, C. 2017. Postgraduate Scholarships Grant - Aboriginal and/or Torres Strait Islander Health Research Scholarship. National Health and Medical Research Council, ($86,117).

Table of Contents

Page

Acknowledgements ii
Abbreviations iv
List of Tables vi
List of Figures vii
List of Publications viii
List of Congress Papers viii
Grants and Awards ix

CHAPTER 1 13
1.1 The Context 14
1.1.1 Injuries in Children 16
1.1.2 Burns in Children 18
1.1.3 Burns in Aboriginal and Torres Strait Islander Children 21
1.2 Understanding the Gap 22
1.2.1 Health Inequities, The Social Determinants and Gradient of Health 22
1.2.2 Multiple Determinants of Indigenous Health 26
1.2.3 Aboriginal and Torres Strait Islander Child Well-being 33
1.1.4 Inequity Manifestations 36
1.1.5 Out-of-Pocket Healthcare Expenditure 37
1.4 Thesis Aim and Structure 40

CHAPTER 2 41
2.1 Preamble 42
2.1.1 Summary: Weaving the Interface 42
2.2 Abstract 44
2.3 Introduction 44
2.4 Methods 46
2.5 Results 50
2.6 Discussion 55
2.7 Conclusion 58

CHAPTER 3 60
3.1 Preamble 61
3.2 Part A: Theoretical Framework Underpinning Methodology 62
3.3 Part B: Indigenous Research Methodology – Weaving a Research Interface 66
3.3.1 Abstract 66
3.3.2 Introduction 67
3.3.3 Research at the Interface 69
3.3.4 Weaving a Methodology 71
3.3.5 Weaving 72
3.3.6 Weaving for Research at the Interface 76
3.3.6 Conclusion 80
3.4 Part C: Textiles for the Woven Research Interfaces in this Thesis 80
3.4.1 Indigenous Textiles (Red) - Indigenous Research Methods 80
3.4.2 Western Textiles (Yellow) 86
3.5 Methodology Summary 89

CHAPTER 4 91
4.1 Preamble 92
4.1.1 Summary: Weaving the Interface 92

4.2 Abstract **99**
4.3 Introduction **100**
4.4 Methods **101**
4.5 Results **103**
4.6 Discussion **109**
4.7 Conclusion **111**

CHAPTER 5 112
5.1 Preamble **113**
5.1.1 Summary: Weaving the Interface 113
5.2 Abstract **120**
5.3 Introduction **120**
5.4 Methods **122**
5.5 Results **123**
5.6 Discussion **129**
5.7 Conclusion **133**

CHAPTER 6 135
6.1 Preamble **136**
6.1.1 Summary: Decolonising Methodology 136
6.2 Abstract **139**
6.3 Introduction **139**
6.4 Methods **140**
6.5 Results **141**
6.6 Discussion **145**
6.7 Conclusion **147**

CHAPTER 7 149
7.1 Preamble **150**
7.1.1 Summary: Weaving the Interface 150
7.2 Abstract **155**
7.3 Introduction **155**
7.4 Methods **157**
7.5 Results **160**
7.6 Discussion **163**
7.7 Conclusion **165**

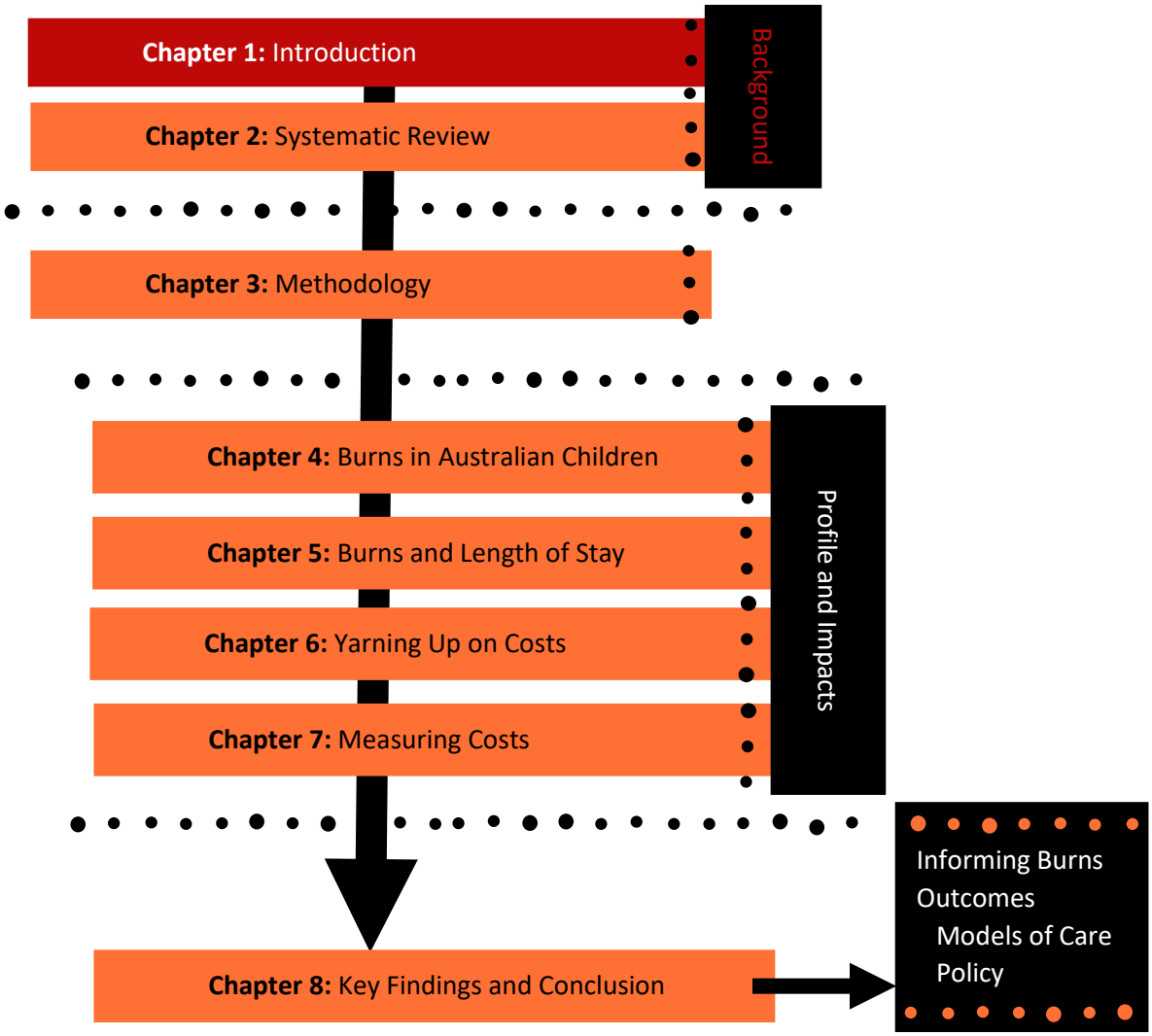
CHAPTER 8 167
8.1 Key Findings **168**
8.2 Implications, Recommendations and Future Directions **171**
8.2.1. Decolonising Research 171
8.2.2 Decolonising Quantitative Measures 173
8.2.3 Health Equity 176
8.2.4 Power 179
8.3 Strengths and Limitations **181**
8.4 Personal Reflection **183**
8.5 Concluding Remarks **188**

CHAPTER 9 190
9.1 References **190**

APPENDICES 212
Appendix A: Patient inclusion process for BRANZ data (Chapter 4 and 5). 213
Appendix B: Variables extracted and created from BRANZ data (Chapter 4 and 5). 214
Appendix C – OOPHE Study Participant Information (Chapter 6) 216
C.1 Participant information Sheet 216
C.2 Participant Consent Form 218
C.3 Yarning Script 219
Appendix D – OOPHE Survey & Expert Panel Documents (Chapter 7) 221
D.1 Expert Panel Invitation 221
D.2 Expert Panel Instructions 222
D.3 OOPHE Survey 224
D.4 Item Refinement Diagram for EFA 246

CHAPTER 1

Introduction and Outline



1.1 The Context

"I am a child of the Dreamtime People

Part of this land, like the gnarled gumtree

I am the river, softly singing

Chanting our songs on my way to the sea

My spirit is the dust-devils

Mirages, that dance on the plain

I'm the snow, the wind and the falling rain

I'm part of the rocks and the red desert earth

Red as the blood that flows in my veins

I am eagle, crow and snake that glides

Through the rainforest that clings to the mountainside

I awakened here when the earth was new

There was emu, wombat, kangaroo

No other man of a different hue

I am this land

And this land is me

I am Australia".

Spiritual Song of the Aborigine (sic)

by Hyllus Maris [4(p. 2)]

Yorta Yorta Elder

Activist, Poet and Educator

(1933-1986)

As descendants from the longest and continuing civilisations this world will ever see, Aboriginal and Torres Strait Islander children always have and always will be considered an important gift for community [5]. While our children come from us as their parents, they are also part of our extended family and connected to our community in so many different and dynamic ways. For example, our extensive kinship relationships establish caring and nurturing roles across the life cycle, from early attachment and bonding of Mums, through to adolescent roles in caring for Elders in later life [6]. These kinship relationships are important for identity development, strength and resilience, which are protective factors for a child's health and well-being [7].

With these factors in mind, our Aboriginal and Torres Strait Islander children have a significant and important role to play, for they are the caretakers of the future. As First Nations parents and community members it is important for us to ensure that there is a path to follow, to protect, nurture and support our Aboriginal and Torres Strait Islander children, allow them to dream big, achieve high and reach their full potential, whatever or wherever that may be. We must also keep them grounded, guide and impart knowledge to our children, so they can succeed with their great responsibility of the future.

Aboriginal and Torres Strait Islander peoples make up approximately 3.3% of the Australian population[6, 8]. Of the overall Aboriginal and Torres Strait Islander population almost 34-40% ad children under 15 years of age, which is a far greater proportional that other Australian children (18-20%)[6, 8]. Unfortunately, this young age profile reflects the lower life expectancy of Aboriginal and Torres Strait Islander people nationally, our health and well-being continually under threat from colonisation. Further to this, social exclusion indicators, such as lower numeracy and literacy levels and anxiety induced by racism and financial hardship, also reflect the significant disadvantage that Aboriginal and Torres Strait Islander children face daily [7, 9-12]. Indicators generated and reinforced by the Australian colonial system, they also represent continual transgenerational trauma and marginalisation. However, despite this significant adversity, Aboriginal and Torres Strait Islander children are strong and resilient, demonstrating higher levels of social consciousness (compassion, empathy and caring) than other Australian children [7, 10]. The strong family connections and networks that most Aboriginal and Torres Strait Islander children are born into provide strength and protection, assisting a child to grow in the areas of sharing, helping and overall mental health and well-being [13].

> *"Children keep us grounded. They help us to enjoy the simple things in life and give to us the greatest gift of all, the chance to love and nurture a new little spirit, a little person who will be totally dependent on our care. In turn they will look at us and smile, bring light into our lives and give us the opportunity to experience unfettered joy as they reach out and touch our hearts".*

Professor Helen Milroy [6(p. 121-122)]
Professor of Child and Adolescent Psychiatry
National Mental Health Commissioner

1.1.1 Injuries in Children

"If a disease were killing our children at the rate unintentional injuries are, the public would be outraged and demand that this killer be stopped".

C Everett Koop

Former US Surgeon General

As cited in Girasek [14(p. 71)]

Injuries are the leading cause of childhood mortality, killing more than 2000 children under 14 years of age daily [15-17]. In addition to these high mortality rates, millions of children are hospitalised for non-fatal injuries, often leaving these children with lifelong disabilities [15-17]. The mechanism of injury follows two distinct pathways of intent in children:

1. Unintentional (accidental, not intended to cause harm), such as traffic accidents, burns, sports-related, falls, drowning, suffocation and poisoning [15, 17].
2. Intentional (premeditated, deliberate, intended to cause harm or death), such as assault, mental violence, suicide, inflicted injury, neglect or negligent treatment, maltreatment or exploitation (including sexual abuse), and war [16, 17].

Unintentional injuries account for 90% of injury cases in children and internationally are the leading cause of mortality in children from 10-19 years of age [15]. Intentional injury remains hidden internationally, partially because reporting avenues for both the victim and perpetrator remain unsafe or untrustworthy [16]. In 2002, the World Health Organisation (WHO) reported that 53,000 children succumbed to homicide internationally, however, due to challenges of identification and reporting this is likely to be a gross underrepresentation [16].

Internationally, injury has been visually depicted through an 'injury pyramid' or 'injury mountain', Figure 1[16, 18, 19], where:

" …with the smallest group, that of death, at the top, hospitalized injury in the middle and the largest group, non-hospitalized injury, at the base". [15(p. 5)]

Some of the children located midway up the mountain (hospitalised), will face profound lifelong physical and psychological disabilities from their injury [15]. These factors trigger immeasurable impacts on individuals, their family and even their community, over the course of their lifetime [15, 16].

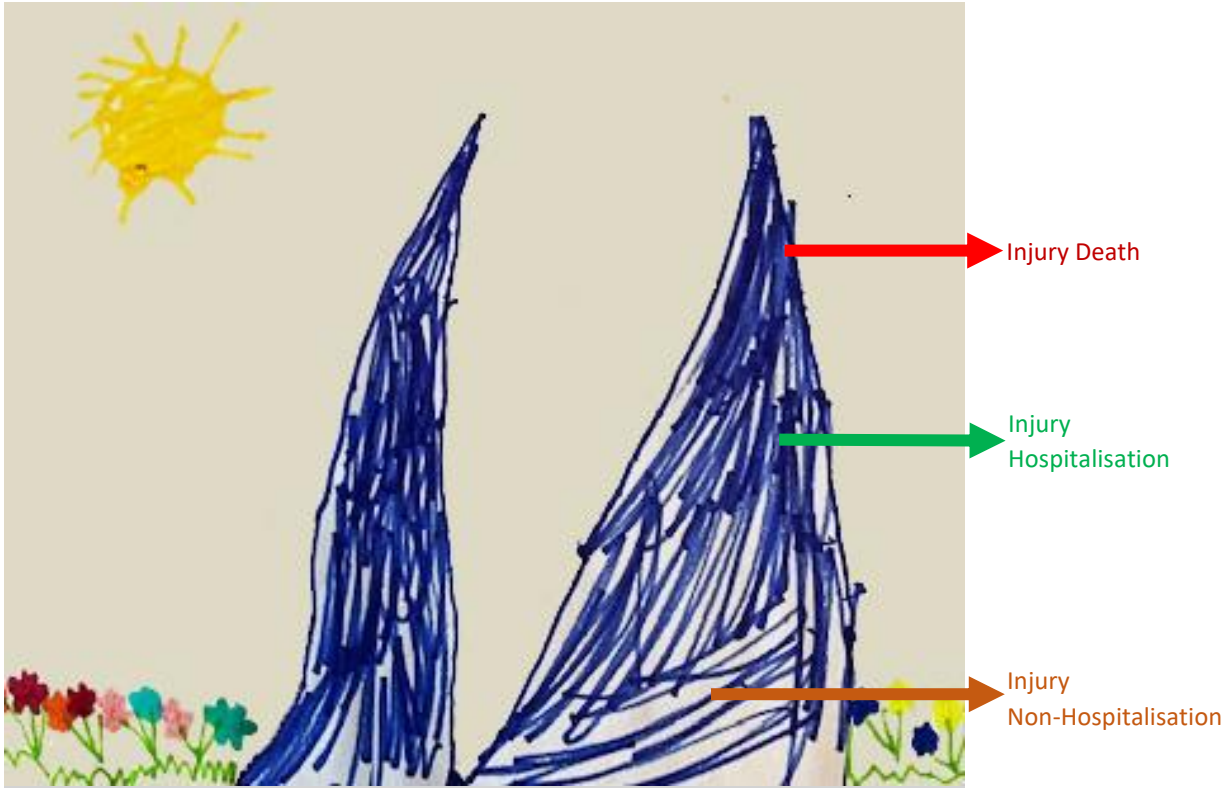


Figure 1: The child injury mountain (or pyramid) [15, 16, 18, 19]. Artist: Charli Ryder, aged 5.

Internationally, road traffic injuries (33%) are the most common cause of unintentional death in children under the age of 19 years, followed by drowning (22%), fire (14%) and falls (8%) [15, 20]. Males are overrepresented across all forms of unintentional injuries [15]. Children under the age of four are also the most vulnerable to mortality from injury [15, 20]. Intentional injuries are different, and an underrepresentation is likely to be reported, but WHO data from 2002 has estimated [16]:

- 150 million girls and 73 million boys experience sexual violence
- 140 million girls have experienced female genital mutilation
- 218 million children have been forced into childhood labour

In the statistics for intentional and unintentional injury, a social gradient exists, reinforcing health inequities for children. For instance, an inverse relationship exists between socio-economic status (SES) and childhood injury mortality and morbidity, in that death, burden and risk is greatest in children from low SES areas [15, 21-23]. Residential location for children has also been associated with injury risk, with higher risk for children in geographically remote regions [15, 24]. Health inequities also exist for injury mortality, burden and risk based on gender, with reported mortality rates and risk being greatest in boys [15].

In Australia, injury is the leading cause of death in children under 16 years of age, and for every death, around 13 other children are hospitalised for minor to moderate injuries [25]. Similar to the international demographics, males are overrepresented, accounting for just over half of injury hospitalisations in Australia [25]. Falls (38.4%) are the most common cause of hospitalisation for unintentional injuries in Australian children, followed by inanimate mechanical forces (17.6%), transport (13.7%), poisoning (3.7%) and burns (3.2%)[26]. Children who are 11-16 years (41%) of age are overrepresented for injury hospitalisations, followed by 1-5 years of age (30.9%)[25]. The majority of children hospitalised for an injury in Australia reside in urban or metropolitan areas (70%), where 40.1% of children are described as coming from a low income background. Hospital length of stay (LOS) for Australian children on average is 1.53 days for males and 1.46 days for females [25].

1.1.2 Burns in Children

Internationally, burns are a significant public health concern, as the eleventh leading cause of mortality in children 1-9 years of age [15]. More generally, burns have been described as one of the most painful injuries to endure and as a resource intensive injury, recovery can take months to years, creating significant social and occupational restrictions on burns patients [15, 27]. A social gradient exists globally for burns injuries, with the rate of child mortality being eight times higher in low to middle income countries as compared to high income countries (Figure 2)[28]. This childhood mortality varies across regions of low to middle income, as depicted in Figure 2, with a clear link to material deprivation, such as SES, parental education level, and household income [28].

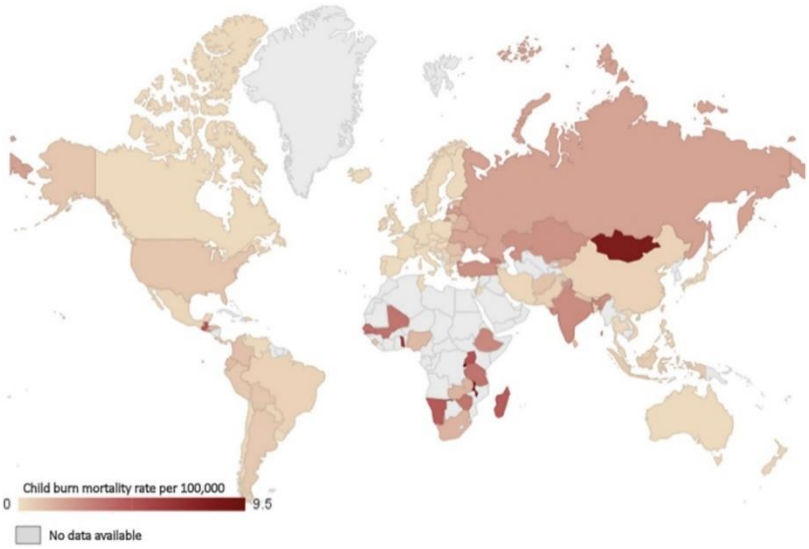


Figure 2: Distribution of child mortality from burns globally in 2013, Image source: Sengoelge 2017 [28(p. 116)]

Child burns incidence is greatest internationally, in children who are five years or younger, of female gender, in low SES populations, and are primarily due to scalds [29-36]. Burns are the only injury in which gender health inequities are reversed, with girls having higher reported rates [15]. This gender difference is prevalent in reporting from low to middle income countries, with higher rates in South-East Asia and Eastern Mediterranean regions [15]. Cultural practices, along with sex-role socialisation, is suggested as a reason for these higher rates, with adolescent girls helping with maternal tasks, ie cooking, as well as child exploitation through the forced marriage of adolescent girls, who are then required to take on household tasks or from bride burning, a form of domestic violence through the burning of new brides by their husband, which can be related dowry payments[15]. Generally, in lower income regions, higher mortality rates are reported from burns injuries [37].

The rate of burns incidence, severity and mortality is on the decline internationally [29, 35, 36, 38]. Despite this decline, in high income countries, burns are still reported as the leading cause of Emergency Department (ED) visits in these countries [39-41]. Burns remain a leading cause of mortality and disability in children, even in high income countries such as America, Canada and Australia [31, 42-44]. Furthermore, in younger children under five years of age, burns are the second most common cause of unintentional death, with the all-cause mortality rates of children who have sustained a burns injury being 1.6 times higher than children who have suffered no injury [39, 40]. On average, 10% of all burns cases in children are life-threatening, requiring hospitalisation for over a week, with the median LOS for children reported as 10-12 days in Europe, 8-13 days in America and 8 days in China [29, 45-47]. While severity is likely to impact on hospital LOS, internationally, these differences in rates may be reflective of different clinical management guidelines and procedures for burns management in children. This is likely to be reflected in the cost of burns treatment across countries and there is consensus that burns are one of the most expensive injuries to treat. The average cost for treating a patient with a burns injury in a high income country is $88,218 USD ($128,364 AUD) [a] [48]. Specifically, for children in America the mean cost for burns injury treatment, which includes follow-up treatment, is $83,535 USD ($122,796 AUD)[b]. In Australia, costs related to treatment for acute burns injuries are estimated at $16.8 million per annum ($15.1 million USD), with the average major burns treatment costing $42,862 ($38,572 USD)[c] [49]. However,

[a] Based on 2012 US Currency Rate
[b] Based on 2006 US Currency Rate
[c] Based on 2010 US Currency Rate

this costing is for acute burns admissions only, and these figures are likely to be an underestimation of the true cost of burns injury treatment in Australia.

During 2017-18, burns injuries in children accounted for 29% of all recorded burns cases in Australia [50]. With a similar epidemiological profile to international trends, there were higher rates of hospitalisation for those aged 1-5 years, of male gender and lower SES, percentage total body surface area (%TBSA) below 10 and in children who reside in a metropolitan location [49-52]. For children and their families, burns can be emotional, traumatic, costly and pose significant occupational and social limitations as well as chronic disability, despite the majority of recorded Australian cases being unintentional [40, 50, 51, 53]. Certainly, Australian parents and their children have reported emotional, social and behavioural struggles for some time after their burns injury [54]. This is similar to other international reporting which has found up to 47% of parents experience clinical symptoms of post-traumatic stress disorder up to three months after the injury, and these symptoms can persist for up to seven years in some parents [27]. Health outcomes related to recovery, such as functional outcomes or health-related quality of life outcomes (HRQoL), can be impacted in children with a burns injury. Long-term scarring as related to physical appearance, has been found to impact on HRQoL in Australian children recovering from a burns injury [54]. In children, decreased measures for HRQoL have been found to be associated with activity inhibition, sleep disruption, increased levels of anxiety and depression, school absences, along with significant indirect healthcare costs [55]. In addition to this, the family environment into which children are discharged can also have a significant impact on recovery, where certain family characteristics, such as positive family cohesion, can have a positive impact on physical and emotional recovery in children [56, 57].

Hospital LOS for burns injury is also suggested to be a predictor of psychological, HRQoL and functional outcomes for recovery, where longer LOS is associated with poorer outcomes [58-61]. Internationally, in high income countries hospital LOS rates for burns injuries are suggested to be on the decline, but this is not the case in Australia [38] with hospitalisation rates and median LOS between 2002-2012 remaining unchanged [35, 36, 49]. In Australia, hospital LOS for children is 2-8 days, but there has been little examination in understanding prognostic factors which contribute to this, or longer hospital LOS in Australian children hospitalised for a burns injury [50, 51, 62, 63]. In international settings, identified prognostic factors contributing to increases in hospital LOS for children include: %TBSA greater than 16; burns cause (scald or flame); full and partial thickness burns[47, 64, 65]. Protective factors for LOS in children include young age and skin

grafting [47, 64, 65]. In Australia, the majority of research surrounding children hospitalised for burns injuries either comes from the Burns Registry of Australia and New Zealand (BRANZ) annual reports, Australian Institute of Health and Welfare (AIHW) reports or is restricted to state or territory linked hospital data [39, 50-53, 62, 63, 66-74]. There are limited national population-based studies in Australia surrounding burns in children [49, 52]. Of the national reports and studies which do exist, many do not focus on exploring health inequities or their manifestations (such as LOS), including the impact on families as a whole [49-51, 53, 62, 66, 67]. Furthermore, there is limited contextualisation for Aboriginal and Torres Strait Islander children, and certainly no research in the quantitative area has engaged with Indigenous research methodologies [63, 68, 75].

1.1.3 Burns in Aboriginal and Torres Strait Islander Children

> *"The injury is having an impact on him being able to do normal things and it's frustrating to him".*
>
> Parent, Coolamon Study Interview

In Australia, burns incidence and severity is greatest in Aboriginal and Torres Strait Islander children [63, 67, 75, 76] who experience burns at 2-3 times the rate of other Australian children [63, 67, 75, 76]. For Australian children hospitalised for their injury, Aboriginal and Torres Strait Islander children have higher rates of flame burns, full thickness burns and burns above 20 %TBSA compared to all other Australian children [63]. Further, the rate of hospitalisation for burns injuries for Aboriginal and Torres Strait Islander children remains double that of other Australian children [63, 67, 69, 75, 77, 78]. This hospitalisation rate, as reported by the BRANZ, is pronounced across all Accessibility and Remoteness Index of Australia (ARIA) areas for Aboriginal and Torres Strait Islander children, intensifying with remoteness [53]. Unfortunately, burns sustained remotely can impact on the injury severity, through limited access to first aid care from amenity restrictions, through to delays in families physically being able to access specialised tertiary services for their child [79, 80]. Depending on the complexity or severity of these burns, Aboriginal and Torres Strait Islander families can initially have extensive hospital stays for initial treatment, with subsequent and prolonged re-admissions for ongoing burns care and scar management. Reporting from the *Footprints in Time* longitudinal study with Aboriginal and Torres Strait Islander children, it was found that 2-5 nights is the average LOS for injury or illness [78]. The median hospital LOS for Aboriginal and Torres Strait Islander children has been reported to be as long as 6.1 nights [63]. This has significant impacts on

Aboriginal and Torres Strait Islander families and their children, such as financial hardship from out-of-pocket healthcare expenditure (OOPHE), isolation from support networks, health and well-being outcomes of parents and children, and a lack of autonomy or self-determination in the treatment and decision-making process.

The only national reporting on burns in Aboriginal and Torres Strait Islander patients comes from the annual BRANZ reports. Aside from this, the majority of the work published is focussed on routinely collected data from Western Australia, hospital admissions data in Darwin (Northern Territory) or linked hospital data from New South Wales [39, 63, 70, 79, 81, 82]. Some of this work has been important in highlighting the health inequities that present in burns injuries for Aboriginal and Torres Strait Islander children. However, to date, this work has not engaged with enquiry which uses Indigenous knowledge, methodologies or research methods. Such an absence of voice reinforces negative discourse for Aboriginal and Torres Strait Islander communities and works against strength-based approaches to research [83-87].

"Nothing about us without us".

Strega and Brown [85(p. 3)]

1.2 Understanding the Gap

1.2.1 Health Inequities, The Social Determinants and Gradient of Health

"Of all the forms of inequality, injustice in health care is the most shocking and inhumane'.'

Martin Luther King Jr 1966

As cited in Zabel & Stevens [88(p.146)]

Factors of biology, genetics and behaviour play a role in ill health and disease manifestation, but for the social, political, economic and environmental circumstances, the conditions in which we live, substantially impact on the overall health and well-being outcomes of an individual and their family, Figure 3[89, 90].

The Whitehall studies on British civil servants during the 1960s and 1980s demonstrated a link between civil servants of lower employment grade and higher reporting of ill health and mortality, which could only be partially explained through individual risk factors (such as obesity, smoking etc)[91, 92]. These studies were instrumental in demonstrating that a social gradient to health exists, where an individual's characteristics are not related to shaping

overall health status, rather it is their social position which is defined by the conditions in which one lives, these conditions being the social determinants [91, 92].

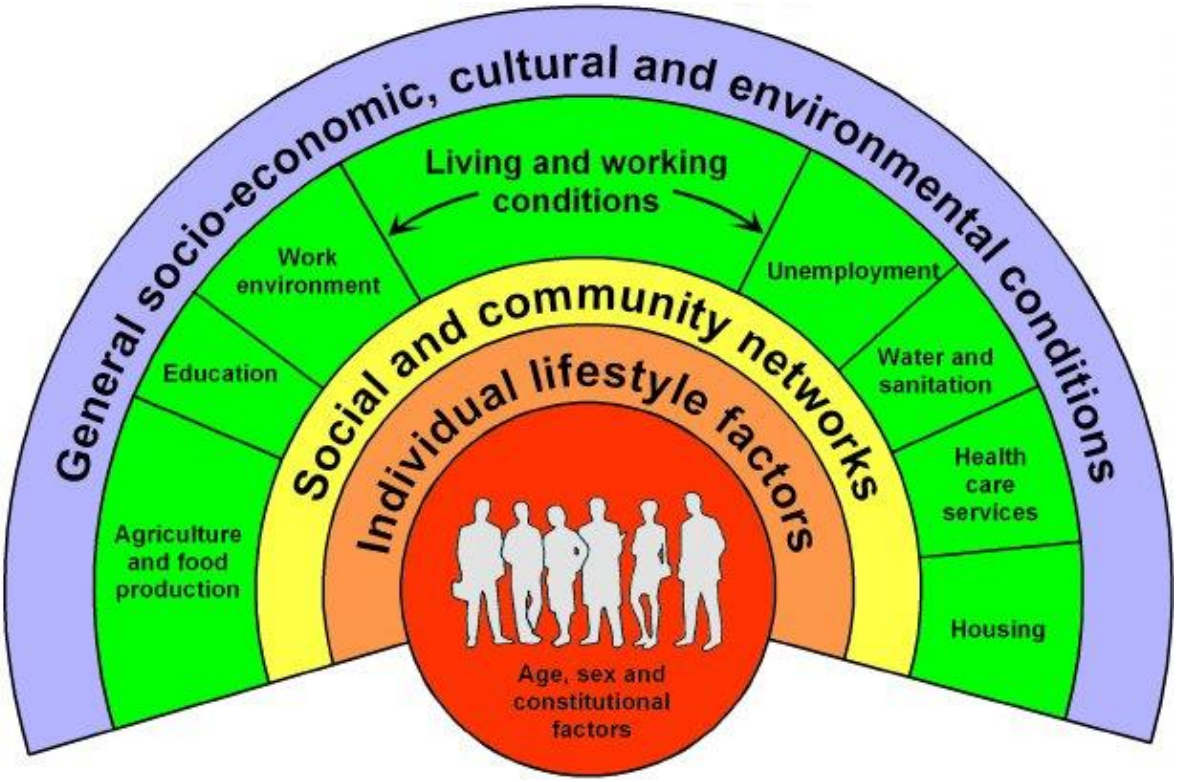


Figure 3: The social determinants of health, image from Dahlgren and Whitehead 1991 [90(p. 11)].

> *"the conditions in which people are born, grow, live, work and age", conditions or circumstances that are shaped by families and communities and by the distribution of money, power, and resources at global, national, and local levels and affected by policy choices at each of these levels".*
>
> World Health Organisation
>
> As cited in Viner at al [93(p. 1641)]

The social determinants of health are 'overarching' conditions, existing above protective factors, individual factors and genetic factors which all contribute to overall health [89, 94]. An array of social determinants of health exist, some of the commonly identified ones are outlined in Table 1.

Social Determinants	Definition
Education	*Education is often regarded as a basic human right. However, access and education attainment are factors often taken for granted. Further to this, there is a link between education level and health status, such that higher education levels allows for better health choices and outcomes [95, 96].*
Employment	*Ability to engage in the labour force, in a safe and supported way, is a well-documented social determinant of health. More recently, this area has focussed on 'precarious employment', covering areas of worker rights (union, industrial action, bargaining agreements), employment security, pay standards (mean salary, gender differences), access, levels of employment (temporary, casual) and powerlessness in the work place [97]. All of these factors have the ability to impact on the health and well-being of an individual and their family.*
Gender	*There are differences in life expectancy between genders, which are not related to biological factors of sex. Gender is a social construct and as such impacts on health in a range of ways [98]. This is not limited to, but includes: labour force engagement, education and healthcare access, risk taking behaviours, sex-role socialisation and disease mongering [98].*
Housing	*Housing can impact substantially on the overall health and well-being of an individual [99]. Factors such as housing security, affordability, location, overcrowding, dwelling quality (structural integrity, materials, sanitation) and access (employment, health, education) interplay to impact an individual's or families health [99].*
Food Security	*Access to affordable and nutritious food, across an individual's life span has been described as a basic human right [100]. In Australia, food insecurity has been strongly linked to SES, and is commonly associated with obesity and chronic disease [101]. Further to this, food insecurity impacts households from low to middle income, and is a known predictor of mental health conditions such as depression [102].*

Table 1: Example of five commonly reported Social Determinants of Health.

Health inequities are the presence of avoidable and discriminatory health disparities [89, 103-105]. Health disparities are preventable and unjust differences (burden, mortality, risk) in the overall health and well-being ('full health potential') between different populations [89]. These disparities exist because of unequal differences between populations in society, such as power, control, ownership, rights, education, SES - factors which all shape the social determinants of health[89, 91, 105]. These factors and their relationships (to other factors, individual or community), can be either protective or combative for health and well-being. Combative relationships are known in the literature as structural inequities, and they target social identity factors such as racism, xenophobia, homophobia, sexism, ableism,

psychophobia, classism etc [89]. Structural inequity manifestations in the social determinants of health reinforce individual health inequities and are empowered through policies (government, corporate, institutional), which support and allow inequitable practises to continue [89]. Examples of this include the exclusion of children with disabilities in injury research studies through to the redevelopment of infrastructure on health (resulting in significant changes to state government policies) and the closure of regional health services in rural and remote areas of Australia [103, 106, 107].

In Australia, an SES gradient exists in childhood injury, where higher proportions of children from socio-economic disadvantaged areas are hospitalised for their injuries compared to those from more advantaged areas [25]. A similar gradient exists internationally, where the greatest injury burden is found in countries of low to middle income countries, where families and children are living in what is described as chronic poverty [15]. Even in high income countries, low SES is a risk for paediatric burns injuries, where disproportionately high numbers of children are hospitalised for their burns injuries, coming from the most disadvantaged socio-economic groups, across all ages [40, 49]. Research central to the social determinants of health and social gradient, focussed on targeting health inequities and breaking the cycle of poverty, has become an important agenda nationally and internationally [3, 105]. Despite this high priority, injury research still has very little focus on the impacts of the social determinants of health, social gradient of health or health inequities on patient outcomes or overall burden (see Chapter 2)[103, 105]. Improving the current situation that children live in, one which acts to diminish structural inequities, has the potential to create a shift in the social gradient, and an overall increase in the health and well-being of the future generations [91].

> *"There's good evidence that if people are disempowered - if they have little control over their lives, if they're socially isolated or unable to participate fully in society, then there are biological effects".*
>
> Sir Michael Marmot [108]

1.2.2 Multiple Determinants of Indigenous Health

> *"As a collective, we can promote understanding of the multiple determinants of Indigenous health — the physical, psychological, social, cultural and spiritual aspects of well-being; ensure … understanding informs clinical interactions .. policy .. resource allocation; advocate … to create reform; and advance an appreciation of the healing strengths of reconnecting …".*

Associate Professor Tamara Mackean [109(p. 523)]
Aboriginal and Torres Strait Islander Public Health
Flinders University

Aboriginal and Torres Strait Islander peoples are the First Peoples of Australia, survivors and decedents of the oldest continuing civilisations of this world [5]. The health and well-being determinants of Aboriginal and Torres Strait Islander peoples are multiple and interconnected (Table 2)[110]. It is imperative to understand that the multiple determinants of health and well-being for Aboriginal and Torres Strait Islander peoples are unique and different to the dominant Australian population [110].

For an Aboriginal and/or Torres Strait Islander individual, overall health and well-being is dependent on a balance between stressors and the ability to cope, which risk and protective factors underpin (Figure 4)[110]. It is also holistic, encompassing more than just the individual, it involves family and community, connectedness and knowledge [111]. In the Aboriginal and Torres Strait Islander health research literature, racism is a common determinant of health [11, 112-114]. In this literature, the clear connection of racism to an individual's overall health and well-being has been made, through decreasing resource access to maintain health (ie employment, housing, healthcare), impacting mental health (ie anxiety, depression), affecting body systems (ie immune, cardiovascular) and facilitating lifestyle behaviours (ie smoking, alcohol)[110, 112, 114]. In this dissertation, however, I have decided to focus on a *strength-based* narrative to describe the multiple determinants of Indigenous health for Aboriginal and Torres Strait Islander communities (outlined in Table 2). This strength-based narrative uses a salutogenesis approach (focussing on factors which are enablers for health and well-being) to examine the literature on the multiple determinants of Indigenous health in Australia. Using this approach, I have sought to provide examples of common multiple determinants of Indigenous health in the literature, which contribute to the overall health and well-being outcomes of Aboriginal and Torres Strait Islander individuals, families and communities [115].

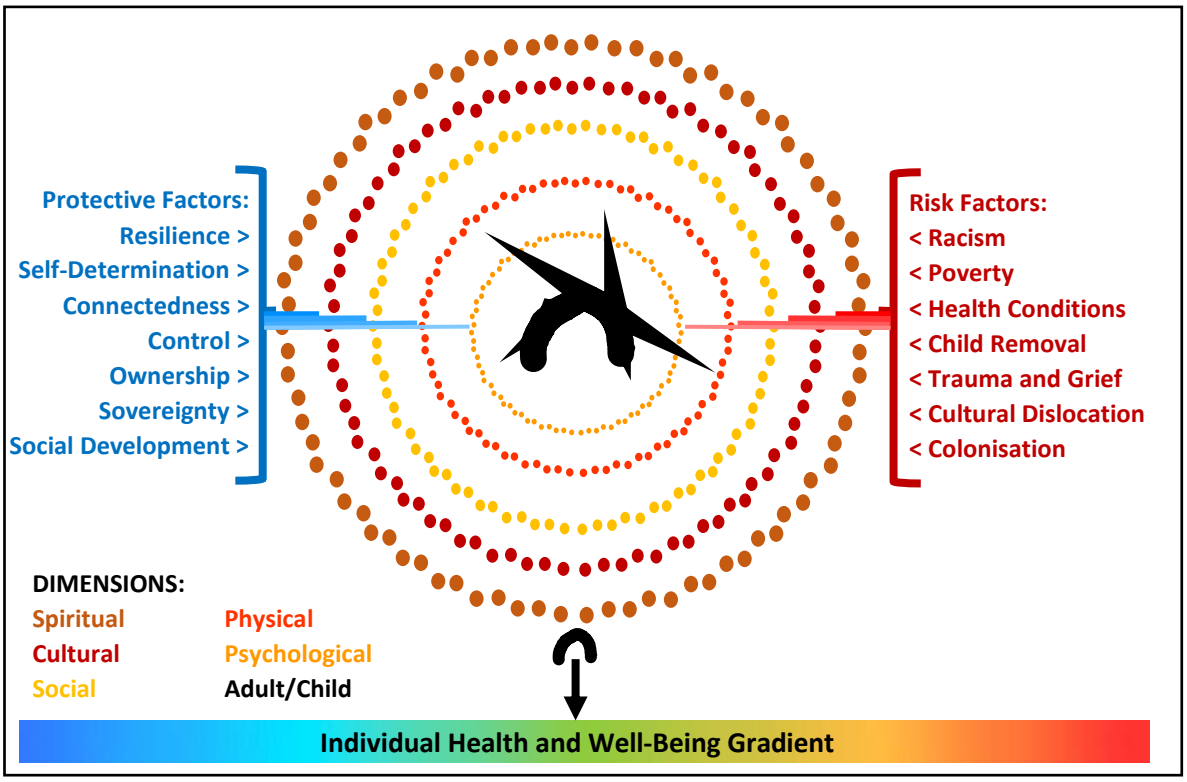


Figure 4: The Balance of Health and Well-being. For an Aboriginal and Torres Strait Islander individual, health and well-being is a balance between the dimensions of life, which are all interrelated (see The Dance of Life). These dimensions, both individually and collectively, are impacted by protective and risk factors from the Multiple Determinants of Indigenous Health [110, 116, 117]. This process is dynamic in nature, forever-changing; it is not static or linear, reflecting that health and well-being of an individual is dynamic and not merely the absence of disease of infirmity.

Multiple Determinants	Description
Community Control and Ownership	*Self-determination and autonomy over land, water, resources and infrastructure are important for the health and well-being of Aboriginal and Torres Strait Islander communities [118]. Recognition and understanding that the social and emotional well-being of Aboriginal and Torres Strait Islander families and children is underpinned by strong and good community governance and leadership is also significant [110]. Community recognition and autonomy through community control and ownership provides significant health benefits. A significant example includes the establishment of the first Aboriginal Community Controlled Health Service at Redfern, to now having over 100 services governed by the National Aboriginal Community Controlled Health Services (NACCHO), who employ a range of Aboriginal Health Practitioners (AHP), Aboriginal Health Workers and Aboriginal Liaison Officers (ALO) nationally.*
Connectedness	*Connectedness to land, family, kin and Indigenous knowledge is important for Aboriginal and Torres Strait Islander peoples, and is central to identity, self-determination and overall well-being [7,*

	[110, 111, 119]. Well-being exploration with Aboriginal and Torres Strait Islander patients living with chronic illness found that cultural connectedness was important in shaping an individual's "spirituality, values, attitudes, concepts, language and relationships to the physical and material world" [120(p. 5)]. In other studies, strong connectedness for Aboriginal and Torres Strait Islander individuals has been linked to a range of well-being indicators, such as: self-esteem, depression, anxiety, type 2 diabetes, falls prevention, cardiometabolic disease, and cardiac rehabilitation [119-124]. For these reasons, connectedness is viewed as a significant protective factor for well-being, and is a key factor for service delivery models and cultural strengthening programs in Aboriginal Community Controlled Health Organisations (ACCHO) nationally [111, 125].
Economic and Social Development	*Independence, self-governance and self-sufficiency agendas should be set by Aboriginal and Torres Strait Islander communities [118]. Communities need to be provided with autonomy and empowerment to achieve this. Economic and social development allows Aboriginal and Torres Strait Islander communities to determine priorities and strategies for their members, be that educational and health programs (ie sports), economic development and infrastructure; this also includes measuring evaluation and success for communities [118].*
Equity	*Equity of basic human rights to which the dominant Australian population is privileged; however, this also includes distinct rights as the First Peoples of Australia [118] for example, equity over basic concepts of law, education, health, access, resources, and infrastructure.*
Resilience	*Resilience, in Aboriginal and Torres Strait Islander communities, is also known as 'strength' or 'survival' and is defined as the strength of Aboriginal and Torres Strait Islander individuals in the face of adversity (ie colonisation, marginalisation, racism)[115, 126]. Resilience is developed through identity and connection, and is used as a way of counteracting risk factors which negatively impact on health and well-being of individuals, families and communities [110, 115].*
Self-Determination	*"Aboriginal peoples have the right to self-determination. A right to negotiate our political status and to pursue economic, social and cultural development".* *Patrick Dodson as cited in Behrendt [118(p. 90)]* *Self-determination for Aboriginal and Torres Strait Islander communities encompasses recognition and support of our cultures. This includes expression, connection and maintenance of traditional practices, cultural dimensions (land, spiritual, kin) and our political rights as First Peoples [110, 118].*

Sovereignty	*"Sovereignty is us as a people being the prior owners of this country and never losing our sovereign rights as that people…. When you talk about self-determination and sovereignty, you are talking about our human rights as the owners of this land".* *Kerry Reed-Gilbert as cited in Behrendt* [118(p. 98)] *Autonomy, a voice, self-governance, recognition of land and dispossession, acknowledgement of ongoing colonisation and transgenerational trauma and grief, basic human rights, self-determination and equality, are all themes common in literature surrounding sovereignty for Aboriginal and Torres Strait Islander communities* [110, 116, 118]*. Sovereignty is also seen as an action for Aboriginal and Torres Strait Islander communities, in being able to exercise autonomy to achieve community aspirations and goals* [118]*. Examples include NACCHO, IndigenousX, and Indigenous Allied Health Association.*

Table 2: Some examples of multiple determinants of Indigenous Health commonly discussed in research with Aboriginal and Torres Strait Islander health.

The multiple determinants of health described in Table 2 are protective factors, working together to improve and strengthen Aboriginal and Torres Strait Islander health and well-being. The way in which these determinants interconnect for Aboriginal and Torres Strait Islander individuals is unique and different. This is the same for how they are negatively impacted by risk factors. In addition, there are overarching elements that are also part of this interaction. For an Aboriginal and/or Torres Strait Islander person to be healthy there needs to be a balance and harmony between "mind, body, spirit and nature"; in this way, health and well-being is holistic for Aboriginal and Torres Strait Islander communities [6]. Professor Helen Milroy, a Palyku woman from Western Australia, child and adolescent psychiatrist, and Commissioner for the Royal Commission into Institutional Responses, best describes this balance and harmony through a multi-dimensional model of health and well-being, "The Dance of Life" Figure 5 and "Dimensions to The Dance of Life" Figure 6 [116, 117].

The Dance of Life (Figure 5), reflects the delicate balance between five critical dimensions (Figure 6) for Aboriginal and/or Torres Strait Islander individuals [116, 117]. Each of these dimensions is not unidimensional: they are multi-dimensional, with intricate and often interconnected layers, very much like a spider's web [116, 117]. The multiple determinants of Indigenous health sit within and across these critical dimensions, acting as protective measures to create balance and harmony in these dimensions. When each of these dimensions is reinstated, repaired, or restored, true healing can start to begin. When balance between these

five dimensions occurs, 'proper'[d] health and well-being can be achieved for an Aboriginal and/or Torres Strait Islander person.

> *"When all of the dimensions are in balance, within the universe, we can break free of our shackles and truly dance through life".*
>
> Professor Helen Milroy [117]

Figure 5: The Dance of Life, by Professor Helen Milroy. Reprinted and described with permission from Professor Milroy [116, 117].

Dimension				
PHYSICAL	**PSYCHOLOGICAL**	**SOCIAL**	**SPIRITUAL**	**CULTURAL**
Born from Country	*Living Life*	*Community Strong Together*	*The Tree of Life*	*Healing Ceremony and Law*

Figure 6: Dimensions of The Dance of Life (painting title underneath image), by Professor Helen Milroy. Reprinted and described with permission from Professor Milroy [116, 117].

There are five essential Dimensions (Figure 6) to the Dance of Life (Figure 5), of which the multiple determinants of health are part [116, 117]. They encompass the following areas:

[d] Proper/proper way – Aboriginal and Torres Strait Islander terminology, implying the correct way of doing or achieving, from a community and cultural perspective.

Physical

"The physical state cannot be entirely separated from the land itself".

Professor Helen Milroy [117]

Aboriginal and Torres Strait Islander peoples are born of and connected to country. This physical connection is significant for providing individuals with strength, grounding and protection [116, 117]. Connection to and caring for country, native title, traditional healing practices (Ngangkari), equitable access, sovereignty and self-determination are important layers to this dimension [116]. Wide-ranging benefits have been demonstrated, linking the practise of caring for country for Aboriginal communities and health and well-being in Australia [127]. Negative layers, which counteract this dimension and impact on health and well-being include land dispossession, damage to country, physical removal, exclusion and marginalisation [116].

Psychological

"The psychological landscape acknowledges the rich two-way connections one makes throughout life from every direction possible".

Professor Helen Milroy [117]

For Aboriginal and Torres Strait Islander peoples, the psychological dimension encompasses connection to mind and emotions, but in the context of one's culture and identity [116, 128]. This involves interconnectedness and kinship relationships, belonging, obligation and reciprocity, community-centred and focussed approaches, and a two-way sharing and learning process [116]. Protective factors for this dimension include equity, human rights, reconnection, acknowledgment of pride, identity building and the recognition of Australia's black history and the ongoing marginalisation it creates [116]. Negative impacts to this dimension include psychological genocide, loss, grief and trauma, identity issues, re-traumatisation, racism, discrimination, marginalisation, illness and misdiagnoses. Currently, Aboriginal and Torres Strait Islander adults experience psychological distress at a rate twice that of other Australian people, statistics which have been borne from the colonisation of Australia [128].

Social

> *" …the central core of the family tree, with its many rings representing the presence of past generations".*
>
> Professor Helen Milroy [117]

For Aboriginal and Torres Strait Islander peoples, community is central. Family exists well beyond 'nuclear' definitions and understandings and encompasses vast kinship relationships and networks [116, 117, 128]. These relationships are important for identity development, grounded strongly in community. Collective approaches and processes, along with two-way sharing, are significant to the social dimension for Aboriginal and Torres Strait Islander communities [117]. Connection or reconnection to family and kin, connectedness, roles and responsibility, self-determination and empowerment are important layers to this dimension. Specifically, in a large subset of urban-based Aboriginal peoples, identity and kinship networks have been closely associated with health and well-being, and also created strength in social capital [129]. Genocide through the forced removal of children, identity renunciation, racism (lateral, internalised and institutional), economic and social marginalisation are just some of the layers which negatively impact this dimension.

Spiritual

> *"… the tree of life connecting the inner core of the earth to the outer dimensions of the universe".*
>
> Professor Helen Milroy [117]

All Aboriginal and Torres Strait Islander peoples are spiritual beings, connected to the oldest continuing civilisations in the world (Bruce Pascoe). Knowing, being and doing are central to spirituality for Aboriginal and Torres Strait Islander peoples and encompasses dreaming teachings and ceremony, belonging, connectivity, beliefs and holistic healing as connected to country [116, 117, 128]. Colonisation has had tremendously negative impacts on spirituality for Aboriginal and Torres Strait Islander peoples, creating spiritual genocide [116, 117]. The resilience of Aboriginal and Torres Strait Islander peoples, however, has helped create a multi-dimensionality to spirituality and identity for some, through interactions with other cultures, be this from the incorporation or separation of religion(s), health and healing processes, and education [128].

Cultural

> *"…the cultural dimension takes the form of three figures symbolising healing, ceremony and overriding all, traditional law".*
>
> Professor Helen Milroy [117]

For Aboriginal and Torres Strait Islander peoples culture is grounded in country, it is where identity, connection and healing come from [117]. From country comes dreaming teachings and knowledge, ceremonies, law and lore [117]. The ability to connect and practice culture, through healing, language, ceremony and education, is important to cultural connectedness, identity and the overall health and well-being of an Aboriginal and/or Torres Strait Islander individual [128]. An overall definition of culture, from an Aboriginal and Torres Strait Islander perspective, goes well beyond the definition provided here [128]. Negative factors contributing to this dimension include racism, tokenism, genocide, misconception and appropriation [116]. Protective factors for this dimension include sovereignty, self-determination, resilience, connectedness, cultural values and identity, community control ownership and governance, and a national identity [116, 128].

> *"..when you're connected to land or country, ocean or water, you're connected spiritually, because they've got spirit in it. When you're happy inside you – that's where well-being comes from".*
>
> Aboriginal Community Member NSW in Davy et al [120(p. 5)]

1.2.3 Aboriginal and Torres Strait Islander Child Well-being

> *"The Oldest Continuing Cultures of the World".*
>
> Uncle Stephen Gadlabardi Warritya Goldsmith[130]
>
> Kaurna Elder
>
> 1957-2017

Australia is a colonised country, and the impact of colonisation continues to impact on the health and well-being of Aboriginal and Torres Strait Islander peoples. Unlike other colonised countries globally, such as Malaysia, the colonisers never left, no treaty was entered into, such as in New Zealand and Canada, thus "sovereignty has never been ceded" [131-134]. In Australia, the processes of colonisation, along with the way in which it produces marginalisation of

Aboriginal and Torres Strait Islander peoples, is well documented [135-137]. This is why there are core accreditation requirements for tertiary level programs (undergraduate, postgraduate, extended training), so that individuals in Australia are educated and understand these atrocities and their continued burden [138]. With this assumption in mind, this dissertation assumes prior knowledge of the reader in this important space.

Aboriginal and Torres Strait Islander peoples are the First Nations peoples of Australia, decedents and survivors of civilisations since time immemorial [5, 133]. In Australia, there are over 300 distinct language groups with 649,200 people identifying as an Aboriginal and/or Torres Strait Islander person in the 2016 Australian Bureau of Statistics census [139]. The definition of health and well-being of Aboriginal and Torres Strait Islander peoples is unique, as the focus is not on disease pathogenesis or Western definitions; rather it is holistic, encompassing and interconnected. This is outlined in the Executive Summary of the National Health Strategy Working Party Report in 1989[140(p. ix)]:

> *"'Health' to Aboriginal peoples is a matter of determining all aspects of their life, including control over their physical environment, or dignity, of community self-esteem, and of justice. It is not merely a matter of the provision of doctors, hospitals, medicine or the absence of disease and incapacity".*

It is from the National Aboriginal Health Strategy Working Party report that the longest standing, most recited and referenced definition of 'health' for Aboriginal and Torres Strait Islander peoples originates[140(p. x)]:

> *"Not just the physical well-being of the individual but the social, emotional, and cultural well-being of the whole community. This is a whole-of-life view and it also includes the cyclical concept of life-death-life".*

This goes hand in hand with their definition of primary healthcare for Aboriginal and Torres Strait Islander communities, which is less commonly cited[140(p. x)]:

> *"Essential healthcare based on practical scientifically sound, socially and culturally acceptable methods and technology made universally accessible to individuals and families in the communities in which they live through their full participation at every stage of development in the spirit of self-reliance and self-determination".*

Since the implementation of the National Aboriginal Health Strategy Working Party, research has exposed a range of factors which contribute to overall health and well-being for Aboriginal and Torres Strait Islander adults, including (but not limited to)[7, 110, 111, 115, 119-124, 126, 141, 142]:

- Connection to Country
- Cultural Beliefs and Knowledge
- Family, Kinship and Community
- Identity and Relatedness
- Safety and Respect
- Sovereignty, Self-determinations and Leadership
- Standard of Living
- Rights and Recognition
- Holistic Health.

These factors are part of the multiple determinants of Aboriginal and Torres Strait Islander health and The Dance of Life, as discussed in the previous section. These factors encompass the four main dimensions of health and well-being for urban based Aboriginal and Torres Strait Islander children outlined by Priest et al (2017) [7]:

- Healthy Body, Health Mind: understanding that keeping the body healthy involved fuelling it right (food and nutrition) and being physically active (sports engagement) assisted in keeping minds strong (social and emotional strength).
- Relationships and Support: connectedness and supportive healthy relationships with family and kin are important for creating overall happiness and well-being. This includes friends and pets and having spiritual connections to family members who had passed.
- Culture and Identity: Aboriginal identity and positive connections to culture and cultural activities are important for overall well-being.
- Worries: stressful life events, loss, death, dying, racism and bullying are all negative risk factors for health and well-being in Aboriginal and Torres Strait Islander children. These risk factors are connected to marginalisation from ongoing colonisation in Australia.

Despite Aboriginal and Torres Strait Islander children having unique and different health and well-being requirements, most research spaces continue to frame the health and well-being requirements of Aboriginal and Torres Strait Islander children from a Western biomedical model, which over-emphasises physical illness [7, 84, 143-145]. Further, there is little examination of

the resilience and strengths of Aboriginal and Torres Strait Islander children [7, 10, 78]. A research narrative that does not capture the health and well-being requirements of its focus population, in this case Aboriginal and Torres Strait Islander children and their families, runs the risk of reinforcing a negative discourse. Such a discourse gives strength to power dynamics, through implicit bias, racism and whiteness. This in turn frames Aboriginal and Torres Strait Islander communities as the cause of their situation, the reason for their marginalisation, and 'normalises' the health inequities that they face. It is a process which can be considered to allow the colonisation process to continue. For the outcomes of this dissertation to warrant any relevance to Aboriginal and Torres Strait Islander health research or Aboriginal and Torres Strait Islander children and their families, Indigenous knowledge (knowing, being and doing) must be central [146]. The narrative must change and decolonisation actions must prevail.

1.1.4 Inequity Manifestations

> *".. living with hardship and discrimination every day of our lives, it means that being sick and disabled is considered normal, and it means constantly losing our family members and friends … What this means in real life is losing our Elders in what should be the prime of their lives … and planning our lives around funerals".*
>
> Dr Puggy Hunter
>
> Chairperson, NACCHO, 1951-2001
>
> As cited in Paul [147(p. 220)]

Power, money and resources impact on the conditions in which individuals are born into, live and pass through [148]. All of these factors interplay, giving rise to inequities which impact individuals, families and communities [148]. For Aboriginal and Torres Strait Islander individuals, families and communities, there are further factors which interplay: colonisation, racism, whiteness and the multiple determinants of Indigenous health, which also produce inequities. The inequities which Aboriginal and Torres Strait Islander communities face are different to non-Indigenous peoples - they are "pronounced, persistent, pervasive" and they are racialised [149, 150]. Examples of these inequities include (as compared to non-Indigenous Australians):

- Lower life expectancy estimated between 8-20 years (highly subjective depending on the resource)
- Lower secondary and tertiary education participation or completion [151]
- Lower labour force participation and household income [151]

- Higher levels of chronic conditions: asthma, heart disease, diabetes, kidney disease, cancers [152]
- Higher incarceration and suicide rates [153, 154].

These inequities are not experienced singularly or in isolation. For Aboriginal and Torres Strait Islander peoples, these inequities work together, creating further manifestations, which creates additional marginalisation and affects the overall health and well-being of an individual, family or community. Examples of such manifestations include:

- Isolation from engagement in community activities which promote health and well-being due to chronic conditions
- A child's identity and connection, from passing of kin (chronic disease, life expectancy, suicide) and incarceration rates
- Available household income, decreasing treatment options for health conditions, further impacted through kin not being able to engage in the labour force due to caring requirements for those suffering from chronic disease.

The studies, which make up this dissertation, focus on examining health inequities related to burns in Aboriginal and Torres Strait Islander children. As outlined in 1.1.3, the known health inequities present in burns injuries for Aboriginal and Torres Strait Islander children include:

- Greater occurrence of burns injuries
- Double the rate of hospitalisations for injury
- Greater burns rates from residences in rural Australian locations
- Longer LOS in hospital for burns injuries.

In addition to examining health inequities, a special focus will be placed on examining one manifestation from these health inequities impacting Aboriginal and Torres Strait Islander families – out-of-pocket healthcare expenditure.

1.1.5 Out-of-Pocket Healthcare Expenditure

Out of pocket healthcare expenses/expenditure (OOPHE) are expenses not covered through universal taxpayer-funded health insurance or private health insurance. OOPHE relates to initial or ongoing treatment for an injury, illness or condition, such as co-payments for medical/healthcare consultations, medical tests, equipment, medications, bandages, transport and accommodation. Additionally, families and households seeking treatment for an illness or injury, can be impacted by indirect costs, such as wage or household income reductions, which further impacts on OOPHE.

When OOPHE are exorbitant, catastrophic healthcare expenditure can occur in households. While a common issue in low and middle income regions, it is an emerging concern impacting families in high incomes countries such as Australia [155-161]. In Australia, this increase has transpired due to an increased reliance on patient or household expenditures, in the form of co-payments and OOPHE, to co-fund healthcare services. Families can experience catastrophic disruption when OOPHE are relatively large when compared to the total household budget [162, 163]. In the literature there is varied consensus on when catastrophic health expenditure is reached:

- 40% of the non-substance spending (total household budget minus food spending) is consumed by OOPHE (Pauly[163] citing Xu et al 2003)
- > 10% of the household budget is consumed by OOPHE [157]
- When households fall below the poverty line from the OOPHE (Pauly[163] citing van Doorslaer 2007).

Regardless of how catastrophic health debt is defined, the outcome for households remains the same where general necessities (food, clothing, accommodation etc) are foregone to cover healthcare expenses [162]. In extreme cases, excessive OOPHE induces bankruptcy and creates poverty, a common example in high income countries internationally, such as the United States or China, resulting from the unaffordability of healthcare insurance and the absence of universal taxpayer-funded health insurance [156, 161]. Major barriers to initial and ongoing treatment for an injury or illness can occur when households deem OOPHE as being too great. In these cases, patients have delayed or not sought treatment for their conditions, or patient compliance with medication has been impacted, through the unaffordability to fill medical prescriptions [155, 161].

In Australia, the taxpayer funded health insurance, Medicare, is available at public hospitals, providing free care at the point of care [155, 164]. The Medicare Benefits Scheme (MBS) covers part of the cost of medical services provided by physicians as well as some diagnostic tests and scans and the Pharmaceutical Benefits Scheme (PBS) covers the cost of pharmaceuticals [164]. Households can also elect to purchase additional insurance coverage through private health insurance, for coverage at private hospitals and subsidies of additional allied health services. Yet despite these measures in Australia, OOPHE is considered high when compared to other high-income countries with universal taxpayer-funded health insurance [155, 165, 166].

In Australia OOPHE research has focussed on the general population or specific medical conditions in Australia. For instance, elderly patients seeking treatment for chronic obstructive pulmonary disease have reported facing economic hardship from OOPHE requirements [156]. OOPHE has caused bankruptcy in some families with no health insurance who areseeking ongoing treatment for ill health [155]. It is this work, which informed a 2014 Senate report on OOPHE in Australia, and contributed to a body of evidence that in part, influenced the Senate enquiry into the OOPHE and the affordability of private health insurance in Australia [167]. Yet little attention on OOPHE research in Australia has focussed on vulnerable populations. For instance, the minimal research which has been conducted with Aboriginal and Torres Strait Islander communities in Australia is polarising. One study found that Aboriginal and Torres Strait Islander patients suffering from chronic heart failure were more at risk of economic hardship in managing their chronic condition as opposed to other chronic disease sufferers [168]. While another study found that Aboriginal and Torres Strait Islander patients receiving treatment for cancer faced reduced OOPHE when compared to non-Indigenous cancer patients, this study only focussed on co-payments for the MBS and PBS which can be subsidised by Close The Gap [169].

Australian research on OOPHE has neglected families with children. Recent work by Cronin et al, investigating healthcare costs and child language difficulties in Australia, found that past research in this area grossly underestimated the bi-yearly healthcare costs for families with children 4-5 years of age (AU$160 vs AU$357-$659), as prior studies had not considered OOPHE in their analysis, such as pharmaceutical costs or early intervention services [170]. Yet often it is assumed OOPHE will be reduced given Australia children under sixteen years of age are bulk billed[e] for general medical visits. It is clear that the limited research in this area fails to consider that OOPHE causes substantial burden and financial hardship on families, especially Aboriginal and Torres Strait Islander families (who economically, and from a social determinants of health perspective are positioned much further down the social gradient and may be sitting on the poverty line) [161, 171]. The current research base on OOPHE in Australia demonstrates that little is known or understood on the impact of OOPHE on Aboriginal and Torres Strait Islander families with children in Australia.

[e] Bulk billed – term used in Australia, where doctors or specialist choose to minimise the cost of the patient, and bill directly to universal taxpayer health insurance (Medicare).

1.4 Thesis Aim and Structure

This thesis aims to provide the first detailed analyses of health inequity impacts on Aboriginal and Torres Strait Islander children who sustain an acute burns injury. This thesis will also explore one health inequity manifestation which impacts on Aboriginal and Torres Strait Islander families collectively, OOPHE. The studies of this thesis engage with interface research methodology, combining Western quantitative and public health knowledge, as well as Indigenous knowledge. This methodology is underpinned and supported by post-structuralism theory.

Chapter 2 (Study One) is a systematic review, investigating how and if health inequities are described or considered in health-related quality of life and functional outcomes in children who have sustained an injury.

Chapter 3 describes how an interface methodology has been used to design the research studies of this thesis.

Chapter 4 (Study Two) examines health inequities in the Burns Registry of Australia and New Zealand impacting Aboriginal and Torres Strait Islander children, with a focus on risks for bacterial infection.

Chapter 5 (Study Three) explores prognostic factors contributing to longer hospital lengths of stay for Aboriginal and Torres Strait Islander children who sustain an acute burns injury. This study uses data from the Burns Registry of Australia and New Zealand.

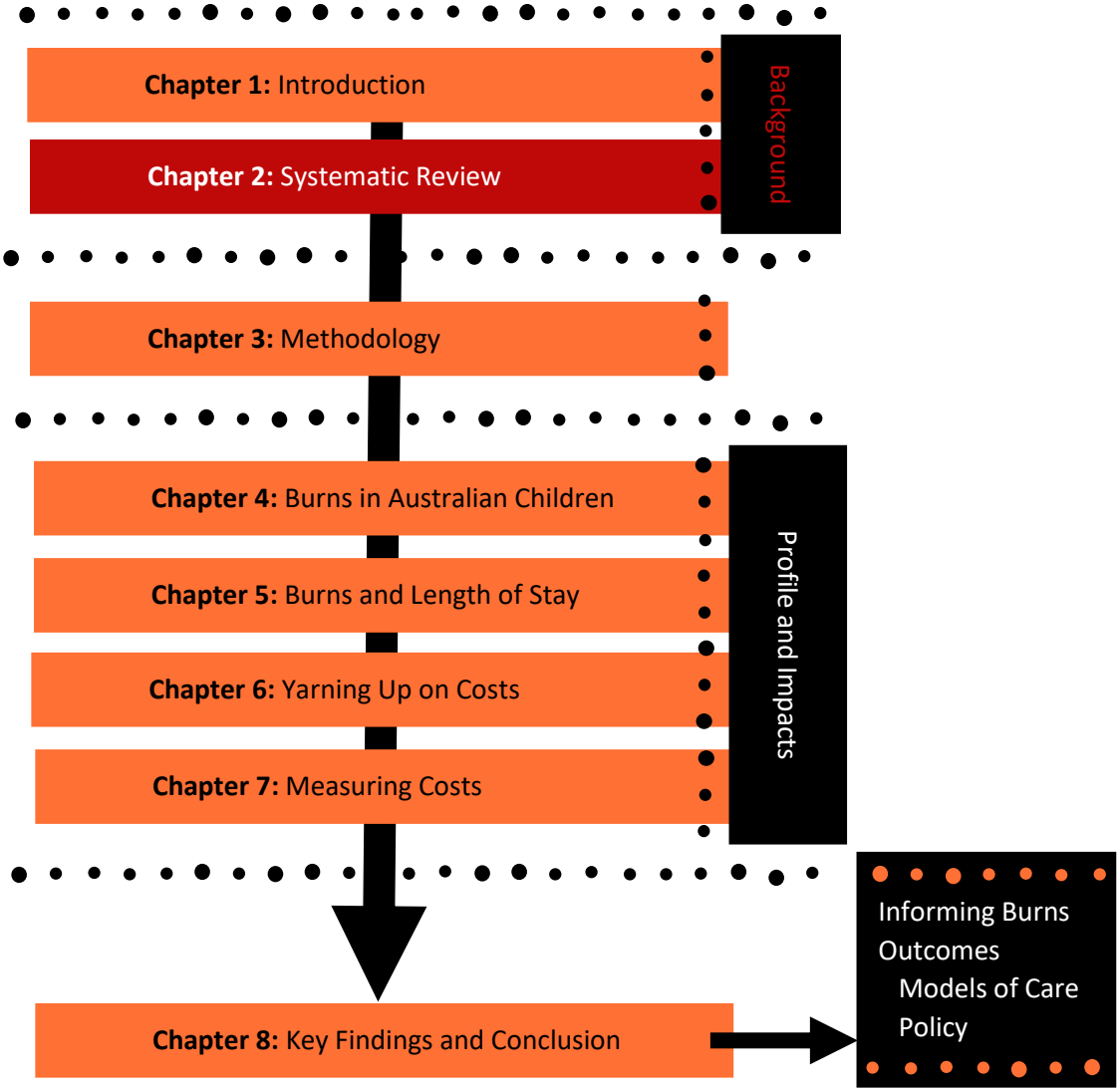
Chapter 6 (Study Four) explores out-of-pocket healthcare expenditure impacts on Aboriginal families whose child has sustained a complex burns injury and received treatment at an Australian hospital.

Chapter 7 (Study Five) describes the creation of an out-of-pocket healthcare expenditure tool which was psychometrically assessed on Aboriginal and Torres Strait Islander families who have children.

Chapter 8 discusses key outcomes, limitations and policy implications from this body of work, along with recommendations for the future of this research.

CHAPTER 2

An Equity Based Review of existing literature on Functional and Health Related Quality of Life Outcomes Following Injury in Children



2.1 Preamble

A systematic review was performed to examine and understand the functional and HRQoL outcomes in children following an injury. A specific focus of this review was to explore how equity was considered or represented in each of the studies. A total of 24 studies were included in this review.

This review was conducted to understand how current injury research describes equity and how it contributes to injury research agendas and outcomes. The outcomes from this systematic review were used to inform studies in Chapters 4-6.

This chapter has been published in:
Ryder, C., Mackean, T., Hunter, K., Williams, H., Clapham, K., Holland, A. J. A., and Ivers, R., Equity in functional and health related quality of life outcomes following injury in children - a systematic review. Critical Public Health, 2019. 30(3):352-366.

Corresponding Author: Courtney Ryder
Published: 26 February 2019

2.1.1 Summary: Weaving the Interface

> *"Disease is perceived fundamentally in a space of projection without depth, of coincidence without development. There is only one plane and one moment. The form in which truth is originally shown is the surface in which relief is both manifested and abolished—the portrait".*
>
> Michael Foucault [172(p .6)]

The research methodology for this thesis is conceptualised through 'research at the interface', using a weaving approach to conceptualise the research knowledge interface (Chapter 3). Although this systematic review is not focussed on studies involving only First Nations or Indigenous peoples globally, Indigenous research methodologies and methods have been used in the contextualisation of outcomes from the results of the review.

The weaving approach drew upon poststructuralism as the theoretical framework which informs the methodology of this thesis, along with Western and Indigenous research methods. Poststructuralism (also referred to as deconstruction) is a critical reasoning process which centrally focusses on unpacking dominant and invisible power and knowledge, such as

embodiment and subjectivity, further discussed in Chapter 3 [173]. Part of this process required focussing on undertaking an equity analysis in this systematic review, consisting of PROGRESS-Plus and an equity lens to explore, unpack and understand the dominant and invisible reporting of equity in injury outcomes in children.

At the research knowledge interface of this study I used Indigenous knowledge, via the Indigenous research methodology of Indigenist research, as defined by Rigney (2001):

- Political Integrity in Indigenous research
- Privileging Indigenous: voices in Indigenist research [174].

This method was used in the context of equity, with an underlying poststructuralism theme. In this process, engagement with equity or the reliability of any equity discussion was considered in line with PROGRESS-Plus and the equity lens integrity; also, how or if an equity voice or viewpoint was considered in study discussion. Principles from the Indigenous methodology, nayri kati, where Western scientific value systems are not the unacknowledged norm, were used with poststructuralism principles at the knowledge interface, to interrogate how equity had been included and engaged with in each of the studies [83]. With this, Indigenous research processes from Yuri Ingarninthi were further engaged to see if equity was being engaged with on a deep or superficial level, or if their equity discussion was used to empower or create further oppression and marginalisation [175]. This research knowledge interface was further informed through the Indigenous research method of Yarning - supervisory Yarning. Allowing the systematic design, analyses and outcomes, to be supported by the collective knowledge of my supervision team [176]. All of these methods were significant in weaving a strong and robust research interface where the 'implicit normalised' process of reporting injury outcomes in children was interrogated against an equity lens. This enquiry examined the centrality of equity to injury outcomes in children, and the often avoided dialogue for equity in this space on an international level.

2.2 Abstract

Injury burden is greater in children from vulnerable and disenfranchised populations. This systematic review aimed to describe injury-related HRQoL and function outcomes in children with a health equity lens. A systematic review was conducted focussing on HRQoL and functional outcomes in children (≤ 16 years), following injury. We applied PRISMA-E 2012 guidelines and the RTI (Research Triangle Institute) item bank for risk of bias and measured equity using PROGRESS-Plus with a narrative synthesis. Of 3013 articles, 24 were eligible for inclusion. Most assessed outcomes following traumatic brain injury (TBI) or burns over a 12-month period. Reduced functional and HRQoL levels pre-injury or baseline, longer hospitalisation and lower SES were linked to poorer long-term outcomes. Measures of equity in methodology, reporting and discussion were limited. Equity variables, such as prior disability, were points for participant exclusion. Ethnicity was often reported only in dominant cultural terms. The equity impact of injury in children remains largely unexplored. Worse injury outcomes were reported in low socio-economic families, but the relationship to other equity variables was not routinely reported. This could significantly inhibit development of targeted preventative programs and health care for those most in need. Injury research agendas need reform; we provide guidance for research teams to assist in including equity in their research and outcomes.

2.3 Introduction

Injury remains a major global public health problem and the leading cause of childhood mortality and disability worldwide [15, 25]. On average, unintentional injury is responsible for 2000 preventable child deaths globally per day [15]. Road traffic crashes, drowning and fire-related burns are the most common forms of fatal unintentional injury in children [15]. With respect to intentional injury, neglect or physical violence are the most common causes of death in children [16]. For every injury-related childhood death, millions of children are hospitalised for non-fatal trauma [15, 16].

Injuries can result in long-term loss of function which may create occupational and social limitations and impact on an individual's HRQoL[15, 25, 177]. The consequences of any injury can impact on the child's ability to attend and engage with school and physical and leisure activities [25, 178]. This may be carried into adult life, impacting on future study, finding work, participating in an active social life and performing everyday activities [177]. These impacts extend beyond the individual to the child's family or carers, causing disruption to general

family life, including the emotional pain associated with a preventable condition through to the financial burden families face for ongoing care [15, 40]. It is not known if these impacts are amplified by social or health inequities.

Health equity is defined as the absence of discriminatory or avoidable disparities in health [3, 104]. Equity variables, such as those of PROGRESS-Plus (residence, race/ethnicity, occupation, gender, religion, education, social-capital, socio-economic position, age, disability, sexual orientation and other vulnerable groups), are used to describe and assess the effect social determinants of health have in population health inequities [179]. Globally, injury burden in children is most significant in individuals from socio-economically disadvantaged or minority backgrounds [15, 180]. Mortality rates in injury demonstrate clear inequities, through gender differentials, where unintentional injury rates are much higher for males but in some injury areas, for example, cases of sexual violence and burns in South Asia, girls are considerably overrepresented [15, 16]. Age inequities exist, with burden greatest in children under five years of age. Cultural inequities occur, where certain populations (ie First Nations children) remain overrepresented [15].

The United Nations (UN) Convention on the Rights of the Child (1989) enshrines the protection of all children who experience injury, through appropriate and safe services and treatment [15, 181]. To reduce injury disparities, injury research should seek to understand and address inequities in injury burden, prevention and care [3, 104]. Such research is paramount in informing government bodies and other stakeholders about where the gaps lie and the support needed to create equity. This can occur through changes to policy and resource allocation that are cognisant of the interplay of the multiple factors of health inequities[3, 104, 182].

Current literature suggests using an equity lens as a way for researchers to understand how equity or inequities are captured in their research and outcomes [3, 112, 182-184]. Despite this, health research, including the systematic review processes, has been criticised for not including an equity assessment [3]. Research which ignores inequities in health and is focussed on dominant biomedical epistemology, analysis and dissemination of study results, including systematic reviews, risks enforcing implicit bias and dominant views [3, 112, 146, 174, 183, 184]. This creates further marginalisation of socially disadvantaged populations and misses the opportunity to better inform health care delivery and planning [3, 112, 183, 184]. Understanding *how current research describes equity and how it contributes* to injury research agendas and

outcomes is critical in creating socially accountable research which supports policy, funding and models of care that are equity inclusive and culturally safe [3, 182]. This systematic review applies a health equity lens to describe the evidence of functional and HRQoL injury burden in children globally.

2.4 Methods

Search Strategy and Selection Criteria

Search terms, including MeSH and Emtree, were developed from key literature in consultation with two specialist librarians, resulting in syntax and terms outlined in Table 3 [15, 180]. Database searches were conducted during August 2017 in MEDLINE (general and In-Process and Non-Indexed Citations), Pubmed, EMBASE, Scopus, Cochrane (CENTRAL), and PsycINFO, focussed on peer-reviewed articles in the period 2000-2017.

Database	Search Syntax (example MEDLINE)
MEDLINE, MEDLINE Epub Ahead of Print, In-Process and Other Non-Indexed Citations, MEDLINE Daily, Pubmed, EMBASE, Scopus, Cochrane Central, PsycINFO.	1. (injur* or accident* or unintentional or traffic or drown* or poison* or burn* or fall* or intentional or physical violence or mental violence or abuse or neglect or negligent treatment* or maltreatment* or suspicious).ab,kw,ti. 2. "Quality of Life"/ or Health Status/ or Health Status Indicators/ or "Activities of Daily Living"/ or Glasgow Outcome Scale/ or Disability Evaluation/ or (Quality of Life or Health Status or Health Status Indicators or Activities of Daily Living or Glasgow Outcome Scale or "International Classification of Functioning, Disability and Health"/ or Disability Evaluation).ab,kw,ti. or (AQoL or PedsQL or BOQ or 17D or SF-36 or QWB or WeeFIM or WHODAS or ICF-CY or PEDI or GMFM or FSS or EDSS).ab,kw,ti. 3. cohort studies/ or follow-up studies/ or exp longitudinal studies/ or prospective studies/ or ((cohort or follow-up or longitudinal or prospective) adj3 stud*).ab,kw,ti. 4. adolescent/ or exp child/ or infant/ or infant, newborn/ or (adolescent* or child* or infant* or preschool* or p?ediatric).ab,kw,ti. not (adult* or elderly or geriatric or wom?n or m?n).ab,kw,ti.. 5. 1 and 2 and 3 and 4 6. limit 5 to (english language and yr="2000 -Current")

Table 3: Search Terms and Databases.

Key inclusion and exclusion criteria were created to capture functional and HRQoL outcomes in injured children (≤ 16 years), from observational (cohort, longitudinal, follow-up and prospective) studies, Table 4. Following guidelines on injury outcome research, all studies needed to include ≥ 3 time points (Table 4), which included baseline < 3 months, rehabilitation/adaptive phase 1-12 months, stable 6-24 months, time points [185, 186].

PRISMA-E 2012 guidelines were followed to carry out the review (Figure 7). The PRISMA-E 2012 is an established framework specific to equity-focussed systematic reviews [3]. No review protocol exists for this review. Title and abstract screening against key words, inclusion and exclusion criteria was undertaken by the lead author (Courtney Ryder). Quality assurance was undertaken through a 'blinded review' process, where the reviewer (Hayley Williams) assessed ten papers which passed or failed against the set criteria. The results from this blinded review were 100 per cent consistent with that of the lead author (Courtney Ryder).

Inclusion	Exclusion
1. All papers focussed on injury. 2. Study inclusion criteria 0-16 years, participants were ≤ 16 years at time of recruitment/baseline measure. 3. Observational studies – cohort, follow-up, longitudinal or prospective. 4. All studies were required to have ≥ 3 time points, which must include: baseline < 3 months, rehabilitation/adaptive phase 1-12 months, stable 6-24 months, time points. 5. Additionally, articles were restricted to published findings in English-language only over the last 17 years (January 2000 – December 2017).	1. Non-injury related studies. 2. Studies reporting on populations above 16 years of age, parents or prenatal were excluded from analysis. 3. Non-observational studies, retrospective studies, or case series. 4. Studies focussed on – study protocols, clinical treatment, clinical guidelines, rehabilitation outcomes and other guidelines. 5. Studies assessing the psychometric properties of HRQoL or functional measures.

Table 4: Selection Criteria for Articles.

Data extracted from articles included reference, study location including country, study type, setting, injury focus, sociodemographic results, outcome measures, study duration, time points (follow-up), participant numbers (baseline, follow up), key findings, strengths, limitations and equity in line with the PROGRESS-Plus approach and Nasser equity lens, and risk of bias [3, 179, 182].

Equity Focus

Equity was assessed in study methodology, design and in outcome reporting of included studies. Guidelines recommended by the Campbell Collaboration and key Cochrane groups were adapted to include the PROGRESS-Plus headings which were used to extract relevant population and individual characteristics [3, 179, 187]. Further factors related to methodology and design, outlined in Table 5, were also recorded for consideration of equity engagement [182].

An additional rating was introduced for each paper based on the equity outputs from

PROGRESS-Plus and Table 5, with a 4-part rating system, providing an overall rating of 'equity examination':

(1) Not evident, no consideration or discussion of equity

(2) Somewhat evident, mentioned in article in one or few areas

(3) Generally evident, equity measures outlined and discussed

(4) Highly evident, equity clearly considered.

Stakeholders
Q. Which stakeholders have been consulted? ie Cultural organisations, patients, clinicians, policy-makers? Q. What participants have been recruited for this research?
Research Team
Q. Does the research team demonstrate diversity and stakeholder accountability? ie Target population is Indigenous peoples; are Indigenous researchers involved in the research team? Q. If diversity is present, in what role is it engaged? i.e. Chief investigator, research assistant, reference group, etc.
Methods
Q. Have appropriate tools and methods been used for the target population? ie Target population is Indigenous peoples; have Indigenous research methodologies been incorporated or considered? Q. What strategies have been developed to minimise participation barriers?
Results
Q. Have variations been considered in terms of culture, equity, social determinant of health?
Outcomes
Q. Have the social determinants of health or health equity been applied to recommendations from results? Q. Are stakeholder voices considered in the discussion and conclusion? ie focus group results review, use of academic sources of literature?

Table 5: Equity Lens – questions developed from Nasser et al 2013 [182].

Narrative Synthesis

A narrative synthesis approach was utilised, given the focus was on describing evidence as related to injury outcomes and equity variables. The approach used in this systematic review incorporated the three-step process described by Popay *et al* 2006 and Petticrew *et al* 2006 [188, 189].

Risk of Bias Assessment

Risk of bias was assessed using the RTI (Research Triangle Institute, California, United States of America) Item Bank, which has been designed to focus on evaluating risk of bias and precision in observational studies through 29 questions focussed over 11 areas, from sample definition to analysis outcome [190]. For this systematic review, the areas of sample definition and selection, exposures, soundness of information, follow-up, analysis comparability, analysis outcome and interpretation were used.

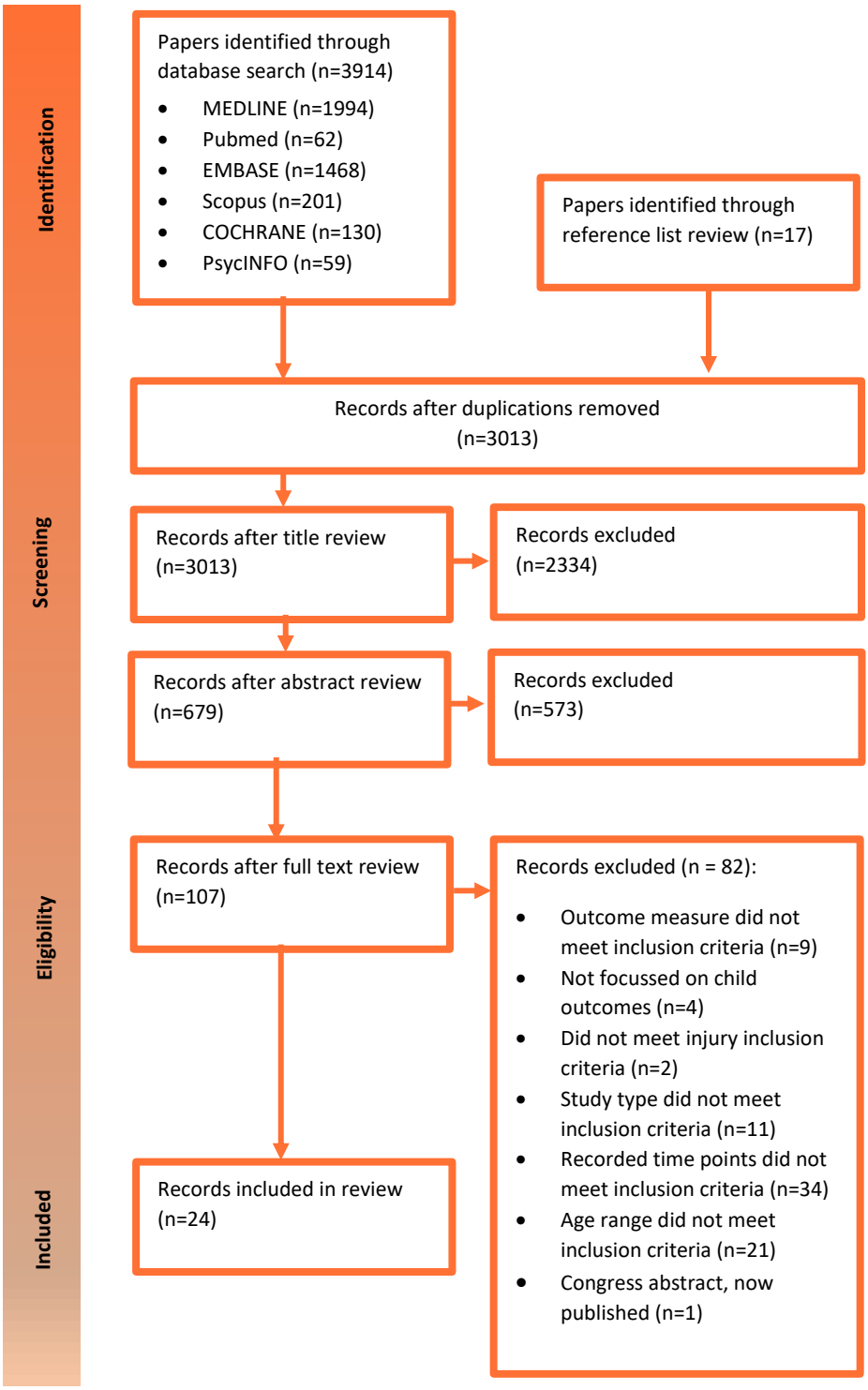


Figure 7: PRISMA flow diagram, PRISMA-E 2012 [3].

2.5 Results

Search Results

The electronic database search returned 3914 records; an additional 17 were identified from reference lists. Duplicate removal resulted in 3013 articles for review. Title and abstract screening removed 2907 records, leaving 107 records for full text review. Full text review of 107 records against full criteria resulted in 24 articles being included (Figure 7).

Study characteristics

Studies (n=21, 88%) were predominantly carried out in high income countries: the United States of America, Australia, Netherlands and Canada, see Table 6 for details. Most studies were described as prospective or longitudinal prospective (n=17, 71%)[191-205].

The majority of studies focussed on TBI (n=14, 56%), followed by burns and injury (both n=3, 13%). Table 6 contains full injury details for studies. Many studies stratified based on injury severity, with %TBSA in burns studies [206-208] and the Glasgow Coma Scale (GCS) in TBI studies [197, 200-202, 205, 208-211]. Control groups were common in TBI studies (60%, n=9) as either healthy or orthopaedic injury controls, matched through age, gender and SES[193, 194, 197, 200-202, 209, 211].

First Author, Year, Country, Study Type.	**Injury, Age, Setting.**	**Outcome Measures (HRQoL and Functional), Follow-up**	**PROGRESS-Plus*** √ - reported, x – not reported, R – Recorded, E - excluded												
			P	***R***	***O***	***G***	***R***	***E***	***S***	***S***	***Plus***				
											1	***2***	***3***	***4***	***5***
Jagnoor. 2017. India. Prospective.	Injury. 8-16 yrs. One hospital.	PedsQL, KOSCHI. Baseline, 1, 2, 4 & 12 months.	√	√	x	√	x	√	x	x	x	√	x	x	x
Schneeberg. 2016. Canada. Longitudinal.	Injury. 0-16 yrs. One hospital.	PedsQL. Baseline. 1, 4 & 12 months.	X	√	x	√	x	x	x	R	x	√	x	x	x
Brown. 2016. Australia. Longitudinal prospective.	Traumatic Brain Injury. 6-14 yrs. Three hospitals.	CHQ-PF50. Baseline, 3, 6, 12 & 18 months.	X	x	x	√	x	x	x	x	x	√	E	x	x
Disseldorp. 2013. Netherlands. Prospective cohort.	Burns. 6m – 16 yrs. Not reported.	WeeFIM. 2 weeks, 3 & 6 months.	X	x	x	√	x	x	x	x	x	√	E	x	x
Yeates. 2012. USA. Prospective cohort.	Traumatic Brain Injury. 8-15 yrs.	CHQ. Baseline, 3 & 12 months.	x	√	x	√	x	R	R	√	x	√	x	x	x

	Two hospitals.														
Palmieri. 2012. USA. Longitudinal.	Burns. 0-5 yrs. Four hospitals.	BOQ. Baseline, 3, 6, 12, 18, 24, 36, 48 months.	x	√	x	√	x	x	X	√	x	√	E	x	x
Anderson. 2012. Australia. Longitudinal.	Traumatic Brain Injury. 2-7 yrs. One hospital.	VABS. Baseline, 12, 30 months & 10 years.	x	x	R	√	x	x	X	R	x	√	x	x	x
Moran. 2011. USA. Prospective.	Traumatic Brain Injury. 8-15 yrs. Two hospitals.	CHQ-PF50. Baseline, 3 & 12 months.	x	√	x	√	x	x	X	√	x	√	E	x	x
Serghiou. 2008. USA. Longitudinal.	Burns. 6m – 16 yrs. Four hospitals.	WeeFIM Discharge, 6, 12 & 24 months.	x	√	x	√	x	√	X	x	x	√	x	x	x
Rotarescu. 2008. Romania. Prospective.	Mild Head Injury. 5-16yrs. Not reported.	SAS. Baseline, 3, 6, & 12 months.	x	x	x	√	x	x	x	x	x	√	x	x	x
Catroppa. 2008. Australia. Longitudinal.	Traumatic Brain Injury. 2-6 yrs. One hospital.	VABS. Baseline, 6, 30 months & 5 years.	x	x	R	√	x	x	x	R	x	√	E	x	x
McCarthy. 2006. USA. Prospective.	Traumatic Brain Injury. 5-15yrs. Four hospitals.	PedsQL. Baseline, 3 & 12 months.	x	√	x	√	x	√	x	√	x	√	√	x	x
Ding. 2006. USA. Prospective.	Fractures. 5-15 yrs. Four hospitals.	PedQL. Baseline, 3 & 12 months.	x	√	x	√	x	R	x	√	x	√	E	x	x
Anderson. 2006. Australia. Prospective.	Traumatic Brain Injury. 2-6 yrs. One hospital.	VABS. Baseline, 12 & 30 months.	x	x	R	√	x	x	x	√	x	√	E	x	x
Strums. 2005. Netherlands. Prospective.	Traffic Injuries. 8-15 yrs. One hospital.	TACQOL. Baseline, 3 & 6 months.	x	x	x	√	x	√	x	√	x	√	√	x	x
Polinder. 2005. Netherlands. Prospective.	Injury. 5-14yrs. 17 sites.	EQ-5D. Baseline, 2.5, 5 & 9 months.	X	x	x	√	x	x	x	x	x	√	√	x	x
Yeates. 2004. USA. Longitudinal prospective.	Traumatic Brain Injury. 6-12yrs. Four hospitals.	VABS. Baseline, 6, 12 months, 4.1 years.	X	√	x	√	x	R	x	√	x	√	E	x	x
Anderson. 2004. Australia. Longitudinal prospective.	Traumatic Brain Injury. 2-6 yrs. One hospital.	VABS. Baseline, 12 & 30 months.	X	x	x	√	x	R	x	√	x	√	E	x	x
Schwartz. 2003. USA.	Traumatic Brain Injury. 6-12 yrs.	VABS.	X	x	x	√	x	x	x	√	√	√	x	x	x

Longitudinal prospective.	Four hospitals.	Baseline, 6, 12 months, 4.1 years.													
Stancin. 2002. USA. Longitudinal prospective.	Traumatic Brain Injury. 6-12 yrs. Four hospitals.	CHQ-PF50 & VABS. Baseline, 6, 12 months, 4 years.	X	√	x	√	x	√	x	√	x	√	E	x	x
Prasad. 2002. USA. Prospective.	Traumatic Brain Injury. 0-15 yrs. Two hospitals.	GCS. Baseline, 3 & 12 months.	X	x	x	√	x	x	x	x	x	√	E	x	x
Kumaraswamy. 2002. Malaysia. Prospective.	Traumatic Brain Injury. 6-13 yrs. Three hospitals.	GCS. 1, 3, 6, 12, 18, 34, 40 months.	√	x	x	√	x	x	x	x	x	√	√	x	x
Stancin. 2001. USA. Prospective.	Fractures. 6-12 yrs. Three hospitals.	VABS. Baseline, 1, 6, & 12 months.	X	x	R	√	x	R	x	R	x	√	E	x	x
Anderson. 2001. Australia. Prospective.	Traumatic Brain Injury. 3-7 yrs. One hospital.	VABS. Baseline, 6 & 30 months.	X	x	x	√	x	R	x	√	x	√	E	x	x

***** PROGRESS-Plus – Place of residence, race/ethnicity, occupation, gender, religion, education, social capital, socio-economic position (SEP), 1 all SEP, 2 age, 3 disability, 4 sexual orientation, 5 other vulnerable group [179].

Table 6: Summary of findings: studies post-injury functioning and HRQoL, with equity in children ≤ 16 years.

Study population and recruitment

Studies varied in their number of recruitment sites, with one site (n=8, 33%) or four (n=7, 30%) being most common; refer to Table 6 for details. Urban-based hospitals were the most commonly reported recruitment site [191-194, 196-198, 200-203, 205, 207-209, 212-214]. Eight years was the average age across all studies, with the most commonly included range at 5-16 years of age (n=13, 52%). Table 6 contains full age descriptions.

Outcome measures and follow-up period

A range of different functional and HRQoL outcome measurements were used (Table 6). The most commonly reported functional outcome measure was the Vineland Adaptive Behavior Scale (VABS)(n=9, 56%)[197, 200-202, 205, 209, 211, 213, 214]. Paediatric Quality of Life Inventory (PedsQL 4.0) was the most commonly reported HRQoL outcome measure (n=4, 36%)[191, 192, 196, 212]. Over half of the studies (n=14, 56%) contained additional assessments outside of functional and HRQoL measures, such as those for family functioning, intelligence, psychological distress, language or auditory skills, development and motor scales [193, 195, 197, 198, 200-204, 209, 211-214]. Limited

studies reported on psychometric property assessment of outcome measures being used and if they had been assessed in the target population or injury population [191, 193, 194, 196, 198-200, 202, 206, 208, 211, 213]. One study questioned the appropriateness of the 'Western-centric' HRQoL measure they used in their low to middle income Indian population [192]. Another study suggested the cognitive and behavioural impacts resulting from TBI injuries rendered their population ineffective in completing outcome measures accurately [202].

Most studies ran over a 12-month period (n=9, 36%) and the majority of studies had 3-4 time points for recording outcome measures (n=20, 83%). Table 6 contains exact follow-up time points. After baseline recording, follow-up was variable between studies, with three months common for second recordings (n=11, 46%)[191, 194-196, 198, 200, 203, 207, 210] and 12 months (n=9, 36%) was most common for the third [191, 193, 194, 196, 200-203, 206]. Reporting on participant numbers for each time point varied across studies, with 48% (n=12) of the studies reporting on participants at each time point [191, 192, 196, 198-201, 206, 207, 210, 212]. While 29% (n=7) reported attrition rates, only 8% of studies (n=2) provided details on attrition rates [200, 212].

Outcomes

Outcome measures of pre-injury HRQoL and functional were indicators of post injury outcomes in 17% (n=4) of studies, suggesting injury outcomes were influenced by premorbid burden [194, 197, 205, 214]. Injury severity and complexity (such as longer hospitalisation or hand burn), affected functional and HRQoL injury outcomes negatively and were indicators for long-term disability in children impacted by injury [191, 195, 197, 200, 208, 209, 211-213].

Most studies reported on time of recovery until 'normal' measures for functional or HRQoL outcomes. Definitions for normal outcomes varied across studies, some used pre-population measures provided by their outcome measures, whereas TBI studies mainly used recordings from matched healthy or orthopaedic injury controls.

Risk of Bias

A low risk of bias was assessed overall in each of the papers. Forms of bias included participant exclusion bias (ie disability or dominant language requirement), demographic and access bias (ie only urban recruitment sites) and attrition (ie higher attrition from low SES and minority backgrounds)[191, 194, 196-198, 200-203, 205, 207, 209-216].

Equity in Study Methods

Most studies (n=19, 76%) ranked poorly (score <2) on equity inclusion and reporting, with equity variables only mentioned infrequently in relation to study homogeneity (n=12) or not at all (n=7)[193-198, 200, 203-214]. No studies reported on engagement or consultation with key stakeholders or the equity composition of research teams. In methodology sections, equity was addressed through standardised measures for socio-demographic information. In this area, study inclusion factors excluded population groups, for instance, 59% (n=14) of studies had a dominant language requirement [191, 196, 198, 200-202, 207, 209-212, 214]. Equity reporting in results focussed on the homogeneity of study participants or participant groups, with only two papers reporting lower SES and ethnic minority status as an indicator for study attrition [194, 201].

Equity in Study Outcomes

Under the PROGRESS-Plus reporting as presented in Table 6, all studies reported on age and gender of children, however 63% (n=15) reported specifically on male gender in their results and not female [191, 193, 194, 198, 200-202, 205-209, 211, 213, 214]. Cultural background (race/ethnicity) was reported in 42% (n=10) of articles, with these studies focussed on reporting either 'white', 'other' or a combination of both (n=7, 70%) and these were not reported in association with study outcomes [191-194, 196, 200, 202, 206, 208, 213]. When 'other' was reported, no studies defined this category.

SES/position was reported in 46% (n=11) of studies, generally USA-based (n=7, 64%), using a variety of tools: Duncan socio-economic index, Daniel's Scale of Occupational Prestige or Hollingshead Four Factor Index [191, 193, 194, 196-199, 201, 202, 205, 209]. A further 16% (n=4) of studies elected to record socio-economic factors but did not include this data in reporting their findings. Education level was reported in 20% (n=5) of studies, with the major focus being on maternal education level [191, 192, 198, 202, 208]. Another 28% (n=7) of studies recorded the parental education level as an indicator of SES for comparing participant demographics for homogeneity [193, 196, 200, 205, 206, 209, 213]. Only two studies reported on geographical location, with one study focussing on rural Malaysian children and the other on Indian children [192, 204]. Disability was a major exclusion factor for studies, with 46% (n=11) of studies' inclusion criteria excluding participants with a pre-existing disability (ie neurological, psychiatric, mental health or developmental disorder) [194, 197, 200, 202, 203, 205, 207, 209-211, 213]. Another 38% (n=9) of studies did not report on disability in their papers [192, 193, 195, 198, 201, 206, 208, 212, 214].

While the majority of studies controlled for equity measures in their population analysis (ie SES, gender), just over a quarter of studies (n=7) factored equity measures into their overall outcome analysis [191, 197, 199-201, 203, 209]. The predominant theme linked lower SES (ie family functioning, lower household resources) to poorer functional and HRQoL outcomes for injured children over time [191, 197, 199-201, 209]. SES was directly reported as a predictor for 30-month outcomes in TBI-affected children [209]. Children impacted by TBI with private health insurance or who lived in two-parent households reported higher HRQoL outcomes, whereas reduced HRQoL outcomes occurred in families reported with poorer functioning [191]. Also, a higher rate of post-injury behavioural problems was reported in children with TBIs who experience greater socio-economic disadvantage and in families with poorer outcomes (high distress and burden)[201].

Equity focus in the discussion and conclusion sections of papers was limited in depth and focus. For instance, one study suggested that overrepresentation of participants from certain minority groups was due to 'rambunctious' play or behavioural problems [206]. Two studies reported an association between injury severity and low SES [197, 200]. One of these studies reported a proportional relationship between injury severity and social outcomes (as part of functional outcome measures) and these outcomes were further impacted by family characteristics (ie resources, functioning)[200]. The other suggested a 'double hazard notion' where negative outcomes transpired from the combination of injury severity and social disadvantage [197]. In another study, girls were three times more likely to report suboptimal functioning in the long term across all health outcome domains as compared to males. In this study it was demonstrated that female gender and hospitalisation were independent predictors for long-term disability [199]. Overall, there was limited discussion on the impact of equity on functional and HRQoL outcomes in children who had experienced injury.

2.6 Discussion

This is the first systematic review to assess functional and HRQoL outcomes following paediatric injury through an equity lens. Results suggested that injury outcomes were influenced by baseline or pre-injury functional and HRQoL outcomes. Increased length of hospital stay, injury severity, lower SES and poorer family functioning were all associated with worse functional and HRQoL outcomes ifor injured children. Reporting on any correlations or associations between equity variables and HRQoL and functional outcomes was limited.

It is clear that the burden of injury is greatest in children from minority or culturally diverse backgrounds [217]. Despite this, the target population in this review, and most child injury studies, continues to be on dominant cultures, predominantly described as 'white'. Furthermore, not speaking the dominant language is an exclusion factor in most studies included in this systematic review. These research practices effectively hide the actual burden of injury in minority populations. This in turn creates clinical and research blindness, reinforcing implicit bias and inadvertently perpetrating institutional racism [112, 138, 183]. Furthermore, it facilitates funding disparities and inhibits policy development and implementation in populations that need it the most [3, 112, 138, 182, 183].

Addressing these deeply embedded practices requires a radical change towards appropriate approaches to research and ethics, starting with engaging with relevant community organisations, stakeholders and key researchers. Changing research practices also requires resources to empower research teams to include minority populations, through training and study opportunities, reference and steering committees, data interpretation from routinely collected data, engaging with appropriate interpreters and/or translation services as well as specialised health services and professionals such as Aboriginal or migrant health workers. This review serves to highlight the need for greater awareness of inclusiveness on the part of ethics committees to encourage and facilitate culturally safe research practices, rather than create additional barriers. Conducting rigorous and high-quality research in high need communities, *with* the community, is more meaningful and respectful and facilitates research translation [218]. It also addresses current equity gaps in research.

Studies have clearly established the link between SES and injury risk and mortality in children [217, 219-222]. Despite this knowledge, this review has identified that there is limited research examining the associations between SES and functional and HRQoL outcomes in injured children. In some studies, the latest versions for SES were not used, for example, studies which used the 1983 version of Daniel's Scale of Occupational Prestige [197, 209, 214]. For this research agenda to be taken further, we recommend using SES measures which are current, using a multidimensional concept of SES, and tailoring to population requirements where needed (ie ethnicity)[219].

Our systematic review found that while boys demonstrate the greatest burden of injury, girls have a higher risk (threefold) of long-term disability following injury [199]. Lack of gender or sex-

disaggregated reporting was common in studies. Such research practice impacts on health research, through sex role socialisation and implicit bias, contributing to health access barriers and further adverse health outcomes [184, 223]. Reporting on sex and gender assists in strengthening the present evidence base, allowing meaningful translation of clinical research into equity targeted health policies [184, 224].

In injury-based research, 'disability' has commonly been used as a way to describe participant outcomes, especially with respect to functional outcomes [225]. In this review, having a disability or mental health condition prior to a child's injury was a major exclusion factor. This practice does not allow a true representation of injury burden. Such approaches can reinforce dominant demographic profiles in injury research and influence clinical guidelines, funding, staff resourcing and policy agendas in this area [3, 182, 225]. Ideally, disability should not be an exclusion factor for injury study participation. Demographic information on a participant's disability and/or mental health condition can be recorded and incorporated in analyses.

We found a level of variability amongst the tools used in studies to measure functional and HRQoL outcomes in injured children. The majority of HRQoL and functional outcome tools applied had prior psychometric property assessment undertaken in dominant paediatric populations (ie USA). Some had additional assessment in particular countries (ie Australia, China) or specific injuries (ie TBI, burns). The type (ie validity) of psychometric property assessment was limitedly reported in studies. Impacts of limited assessment were demonstrated in one study, where a generic HRQoL was used in Indian children. They reported cultural variations in health and well-being impacted on their HRQoL results, suggesting their generic tool was inadequate for use in this population [192]. The majority of studies did not consider the impact of this variability. One study, where psychometric properties had not been assessed in the target injury population, judged their study population incapable of completing their HRQoL tool due to their injury, rather than the tool being unsuitable for use in this injury population [202]. No study undertook a comprehensive analyses of equity impact on HRQoL or functional outcomes.

Currently there are no specific guidelines for longitudinal outcome research in children. A general framework focussed on adult injury-specific follow-up studies by Van Beeck *et al* (2007) exists, but it does not capture the common nuances which present in paediatric studies, for example, parental reporting, childhood development or tool appropriateness. Further

research is required to determine the most effective and appropriate functional and HRQoL measures for use in children, across a variety of injuries and populations. We recommend using more than one standardised tool for functional and HRQoL outcomes and undertaking psychometric property assessment in a small pool of the target population to confirm the suitability of each tool prior to data collection, or designing culturally-validated HRQoL tools.

Strengths and Limitations

This is the first systematic review in this area to use an equity analysis lens. Observational studies were the main focus and defined as having three or more data collection points, across the following three timepoints (Table 4). Targeting studies across specific timepoints is a strength of this study as it decreases the variability between timepoints [185]. Observational studies did not include retrospective studies, which is a limitation of this review. While specific search syntax was designed to comprehensively search databases, some studies may have been missed. Resource limitations in this review may have introduced a level of bias. Not conducting a dual review process at all potential stages risks introducing selection bias, random error and analyses bias into the review [226]. Excluding articles prior to 2000, and the grey literature, also introduces a level of selection bias. Further, a focus on English-only articles can create language bias, although the impact may be comparatively small, however, as recent reviews have demonstrated a decline in the impact of language bias, as even research institutions where English is not the dominant language have moved to publishing in English [227]. In this review, five articles were published in English, where English is not the dominant country language. Some of the studies included in this review did have methodological limitations, for example, only one study site. The review was registered with Prospero, but was not approved as the first database search had already occurred.

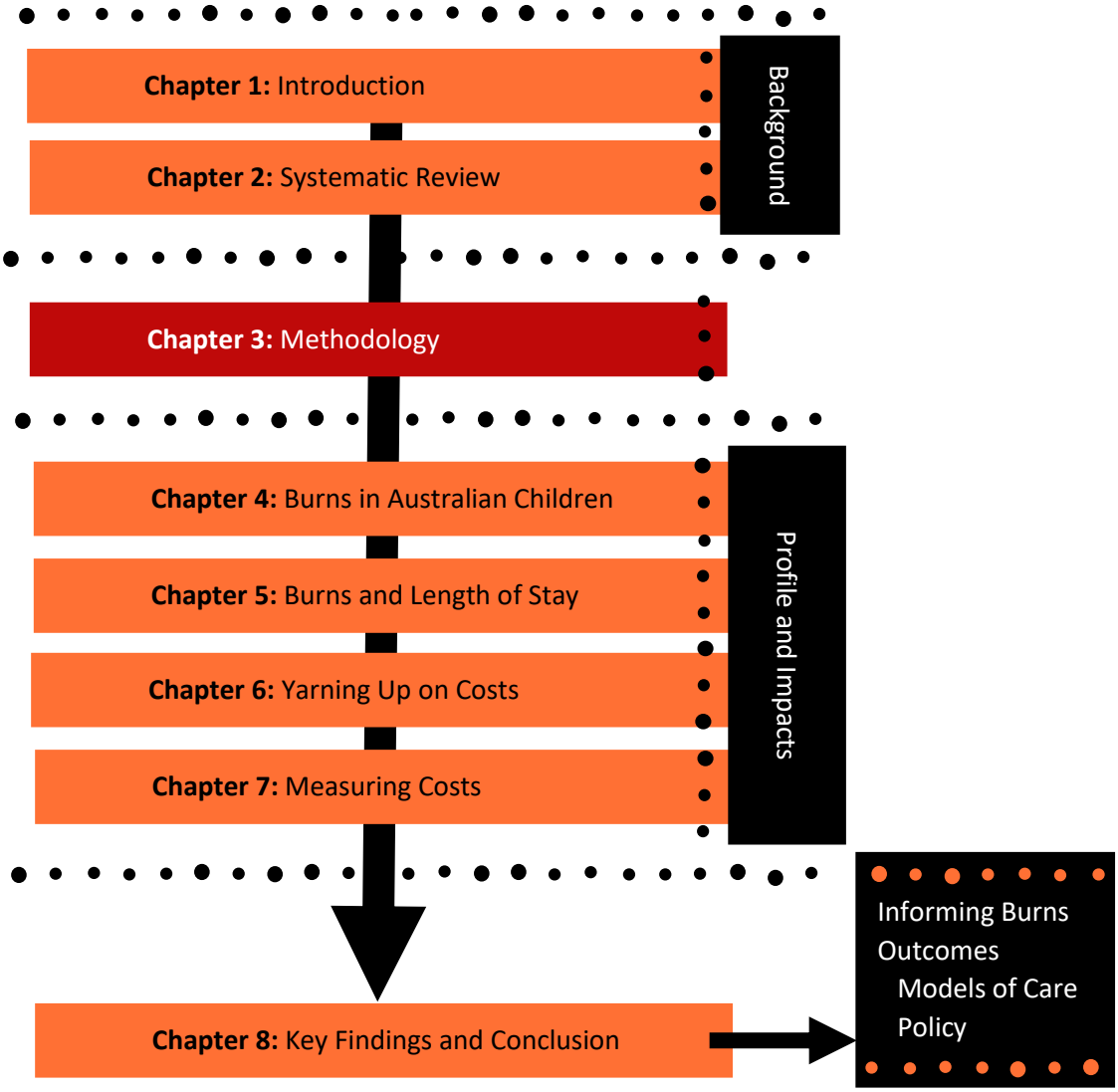
2.7 Conclusion

This review found that pre-injury status, length of hospital stay and injury severity was predictive of recovery outcomes for HRQoL and functional outcomes following injury in children. The review highlighted that few studies have explored the relationship between equity and HRQoL and functional outcomes in injured children. In the limited studies that did examine this link, children from lower socio-economic backgrounds had poorer injury outcomes. This is likely to reflect associations between inequity in access to health care and functional and HRQoL outcomes in injured children. Furthermore, this systematic review identified that most injury research is largely undertaken with a ‘dominant biomedical

research lens'. Excluding health inequities in injury outcome research runs the risk of creating further disparities. We recommend research agendas and teams engage with minority population groups and key stakeholders to ensure appropriate and meaningful research ensues. This should include psychometric property assessment of functional and HRQoL tools in the target population to assess suitability. Measures of disability or mental health conditions should not exclude participants. Disaggregated reporting should occur for sex or gender. Such actions can ensure that research outcomes are effective in making lasting equitable health gains for all children.

CHAPTER 3

Weaving a Methodology for Research at the Interface



3.1 Preamble

This chapter conceptualises and describes my standpoint as an Aboriginal researcher. It is divided into three parts:

3.2 Part A: Theoretical Framework Underpinning this Methodology

A brief introduction on deconstruction and poststructuralism from the teachings of Foucault is provided and how it relates to the methodology in Part B.

3.3 Part B: Indigenous research methodology – weaving a research interface

This section contains an outline on Indigenous knowledge, Indigenous methodologies and Western research engagement with Aboriginal and Torres Strait Islander communities. Its focus is on contextualising '*research at the interface*' or '*knowledge interface methodology*', where Indigenous Knowledge and Western Biomedical Knowledge intertwine.

Part B has been published in:

Ryder, C., Mackean, T., Coombs, J., Williams, H., Hunter, K., Holland, A.J.A., and Ivers, R., Indigenous research methodology – weaving a research interface. International Journal of Social Research Methodology. 2020;23(3):255-267.

Corresponding Author: Courtney Ryder

Published: 26 September 2019

3.4 Part C: Textiles for the Woven Research Interfaces in this Thesis

An outlines of each of the textiles (research methodologies and methods) used to create the knowledge interface of studies from Chapters 2, Chapter 4, Chapter 5 and Chapter 7. Decolonising methodologies will also be outlined which are used in Chapter 6.

3.2 Part A: Theoretical Framework Underpinning Methodology

> *".. Things which seem most evident to us are always formed in the confluence of encounters and chances, during the course of a precarious and fragile history …. It means that they reside on a base of human practice and human history; and that since these things have been made, they can be unmade, as long as we know how it was that they were made".*
>
> *Foucault*[228(p. 36-7)]

The methodology of this thesis is underpinned and influenced by the theories of poststructuralism, enunciated by the late French philosopher, Michael Foucault. Much of Foucault's work explores the construction of what is perceived as 'truth', and the discourse and power which manifests this. While it may seem curious for a female Aboriginal researcher to be influenced by a male French philosopher, the way in which Foucault questions the construction of truth, his deconstruction process and critical analyses resonates with me. It is by no means what he represents, as an individual in society, but rather his teachings and articulation of these teachings which underpin and influence the methodology of the collective studies in this thesis.

Foucault's early work involved 'archaeology' and 'discursive formations' - terms he used to describe the analyses of 'systems of thought', also described as the history of knowledge(s)[229]. His work in this area was particularly focussed on how disciplinary knowledge (systems of thought) functioned, where the term 'disciplines' represent academic or institute (ie medical, corrective etc) [173, 229]. Some of Foucault's work in this area focussed on the discourse surrounding individuals who did not conform to acceptable social norms/categories at that time, such as the madman, patient, or criminal [173, 229]. However, these social norms/categories were defined by disciplines through the power that they held from knowledge formation, for instance the patient, their disease and the penetrating medical gaze of the clinician, which was a process of disciplining/civilising the patient in Foucault's The Birth of the Clinic [172, 173].

It was in this work that the power of the discipline, the process of the medical gaze, neglected or chose not to engage or understand the knowledge that the madman, patient or criminal had on themselves [172, 229]. Foucault describes such knowledge as 'marginal knowledge' as it is knowledge which has been considered as inappropriate or inadequate by the discipline. It is here that Foucault recognises that this marginal knowledge, which has been previously discounted as inadequate, needs to be re-engaged with[229]. It is in this process of re-

engagement that resistance can occur, in which one can 'break free' or redefine power relationships[229].

> *".... a whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated; naïve knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity .. It is through the reappearance of this knowledge, of these local popular knowledges, these disqualified knowledges, that criticism performs its work".*
>
> *Foucault*[229(p. 16)]

For Aboriginal and Torres Strait Islander communities, the process of colonisation has created a situation where a plethora of what Foucault would label "marginal knowledge" exists, generally referred to in the literature as Indigenous Knowledge (knowing, being and doing) and methodologies [230]. As McHoul and Grace describe in relation to Foucault's work, what counts as true or false knowledge is essentially born from prescribed "*social, historical and political conditions*" [229, 231]. This is currently observed in the space of epidemiology and injury research, where Aboriginal and Torres Strait Islander communities are the 'subject', and Indigenous knowledge(s) and methodologies might be considered 'marginal knowledge': disregarded, not engaged with, or engaged with on a very superficial level. Discourse in epidemiology or injury research for Aboriginal and Torres Strait Islander communities more often than not focusses on a 'set process', a 'set technique', a 'set discourse' surrounding the 'discipline'; in this process the discipline is provided the power on "*how human subjects are formed, how institutions attempt to 'normalise' persons on the margins of social life*" [229].

> "*Power .. a network of force relations throughout society, relations that are characterized by resistance and which interact by means of local tactics and larger strategies".*
>
> Foucault's Theory of Power as cited in Taylor [232(p. 14)]

Foucault is best known as a philosopher of power and has described and analysed a variety of power formations. For instance, Foucault's understanding of power through "juridico-discursive" is described in the following five aspects [232(p. 17)]:

1. The operation of power is negative and suppressive
2. Power exists through rules or laws ie illegal vs legal through a given law or rule

3. These two parts allow power to have a cycle of control
4. Power creates suppression through the following expressions – rule/law justification, preventing or denying a narrative
5. Power is overarching and everywhere [232].

His focus on disciplinary power is the power that a discipline (ie institute, academy, government) holds over individuals through set laws or rules, which force individuals to comply with set behaviours. In this process, 'disciplines' bring together various types of knowledge, but only knowledge which reinforces and strengthens the 'power' or agenda of the institution to 'control' the individual [232, 233]. An example, from colonisation in Australia, was the removal of Aboriginal children, who were then institutionalised, to be taught domestic duties, to become the next servant workforce for white Australia.

Disciplinary power is different from Sovereign power, which is focussed on disempowerment and slavery; disciplinary power is power which seeks only to take, but not control [232]. Another example of this is the foundational grounds of colonisation in Australia, 'terra nullius', used by the 'Crown' to take Australia for 'the mother country' where any means necessary were used, resulting in the decimation of Aboriginal and Torres Strait Islander communities.

> *"The sovereign exercised his right of life only by exercising his right to kill, or by refraining from killing; he evidenced his power over life only through the death he was capable of requiring. The right which was formulated as the "power of life and death" was in reality the right to take life or let live".*
>
> Cloë Taylor on Foucault [232(p. 42)]

Unlike sovereign and discipline power, biopower is not focussed on the individual, rather it is focussed on populations and on administering life [232]. It is the constructs related to biopower which inform the methodology of this thesis.

> *"Biopower … functions through norms rather than laws … it is internalized by subjects rather than exercised from above … it is dispersed throughout society rather than located in a single individual or government body".*
>
> Cloë Taylor, Biopower [232(p. 43)]

Biopower does not exist at the academic/institute level (ie schools, hospitals, workshops); rather, it exists at 'the state' level [232]. To be able to deploy biopower, the state uses various techniques or tactics, research being a primary technique, to generate the knowledge used to create biopolitical movements [232]. In this way, research feeds biopower. However, the research that the state needs for biopower must be focussed on populations, ie public health epidemiology using observational or randomised control studies. Through ensuring this process, the gaze is always set, cast away in the opposite direction from the state, only focussed on the target population whom are not afforded the same 'power' as the researcher or the state [229]. An example from the colonisation of Australia, eugenics, phrenology and Social Darwinism are all examples of 'knowledge' derived from research, albeit scientific racism [f]. This knowledge was used by 'the state' (colonisers/Crown) to create biopolitical movements, such as the removal and institutionalisation of Aboriginal children [232]. Thus, a biopolitical movement which allowed for the management of the health, well-being and future, but in reality, the cultural genocide and transgenerational trauma and grief, of generations of Aboriginal children and their communities. This biopolitical movement, while serving the state's agenda of assimilation, was also about protection, the protection of 'the state', the 'whiteness' they represent and their Western approach to life in Australia.

> *"We should admit . . . that power produces knowledge (and not simply by encouraging it because it serves power or by applying it because it is useful); that power and knowledge directly imply one another; that there is no power relation without the correlative constitution of a field of knowledge, not any knowledge that does not presuppose and constitute at the same time power relations".*
>
> *Foucault as cited in McHoul & Grace[229(p. 59)]*

Foucault recognises that wherever power exists, so does resistance, as without the pushing and pulling of two systems of knowledge, power does not exist [229, 232]. The process of 'resistance' is never effective when it targets 'power' alone, but is more effective when it targets the techniques used by disciplines or 'the state' to generate power in the first place [229]. For this to occur, one must critically engage and understand the 'nuances' associated with the

[f] Eugenics, phrenology and social Darwinism are scientific theories, built on race and race based studies of superiority. Xenophobic in nature, their intent to dehumanise any race or culture, which was different from the dominant. The science behind these theories has been disproved, yet remnants live on i.e. survival of the fittest. These theories were used to impose racist policies which marginalized Aboriginal and Torres Strait Islander communities.

'techniques', ie strategies, which produce the knowledge [229]. It is through this process that resistance allows knowledge to be challenged; where the 'normalisation' for the 'correct' and 'functional' fitting of knowledge is questioned; where the 'truth' (or what counts as truth - and why it counts as truth) is examined in the 'discipline' or 'the state' [229]. Subsequently, many 'truths' may in fact exist, but the question surrounding them is which one is the principal truth? Critically, it's also asking or knowing why it is that this truth is superior over the other truths [229].

> *"By Foucault's reasoning, it would appear that the correct appropriation of research methods depends on the nature of the truth that we require, and perhaps more importantly, the truth that is available to us".*
>
> Glyn Winter on Foucault [231(p. 12)]

It is from Foucault's teaching on discourse, truth and power that I set about establishing a new narrative and discourse around Aboriginal and Torres Strait Islander quantitative health research. For this to occur, the Knowledge Interface methodology must be engaged with; one which engages with all of the 'truths' available, incorporating both Indigenous Knowledge, methodologies and quantitative techniques. Through this journey, I seek to answer my research questions with an enquiry process founded in Indigenous Knowledge, and great hope that it will elucidate a 'new principal truth'.

3.3 Part B: Indigenous Research Methodology – Weaving a Research Interface

3.3.1 Abstract

Indigenous research Knowledges and methodologies have existed over millennia, however it is only recently that Indigenous scholars have been able to challenge institutional Western hegemony to reclaim sovereignty in the research space. Despite the high volume of quantitative research describing Aboriginal and Torres Strait Islander health, there has been limited evaluation of the value added through incorporation of Indigenous Knowledges and methodologies. 'Research at the interface' has been discussed as an Indigenous research methodology for researchers to contextualise and inform their research practices, between Indigenous and Western systems of knowledge. In this article we address the significance of 'research at the interface' for Aboriginal and Torres Strait Islander research, as an exciting opportunity for innovation to ensure strength, self-determination and resilience for Aboriginal and Torres Strait Islander communities engaged in research. We also introduce weaving a

methodology for 'research at the interface' as a process for conceptualising Indigenous and quantitative research methodologies at the interface.

3.3.2 Introduction

> *"They also don't understand the difference because they say, "We don't do it … it's not necessary." And you think, it's not altogether true because they don't understand the beginning, and this is because they've been told nonsense in the past and the nonsense they've been told is that one culture is better than the other. This is a lot of nonsense because all cultures are equal ..".*
>
> Uncle Dr Lewis Kauwanu Yorloburka O'Brien,
> Kaurna Elder [175(p. 465)]

Indigenous Knowledges, methodologies and research have always existed. Founded in the oldest continuing civilisations of the world, they are a central part in defining an individual's identity and connection within their community [234]. Fluid and dynamic in nature, this knowledge and these methodologies are 'living knowledge' passed on and through generations forever evolving and growing, never static [235, 236]. Examples of this rich research and knowledge practice, connecting to health and science are well documented over Australia, and include:

1. Healing and medicine, Ngangkari, traditional healers of Central Australia (Anangu[g])[237, 238]
2. Conservation and land management, Fire Stick Farming in Nunga[h] communities of SA [175]
3. Engineering, sustainability and aquaculture, Budj Bim for Gunditjmara People and Narungga Fish Traps, Ngarrindjeri Fish Traps, Torres Strait Fish Traps, Fish Traps in Aboriginal coastal regions of Queensland [239-242].
4. Aboriginal Astronomy, The Ngara Yura Program [243].

Considering the depth and continued development of Indigenous Knowledges and methodologies over millennia, it is only relatively recently that Indigenous scholars have been able to challenge institutional Western hegemony to reclaim a position in contemporary research spaces.

Australia is a colonised country, stolen through 'terra nullius', denying the humanity and

[g] Anangu is a term used to Aboriginal communities and people from Central Australia.
[h] Nunga is a term used to Aboriginal communities and people from Southern South Australia.

sovereignty[i] of Aboriginal and Torres Strait Islander peoples, allowing physical and cultural genocide to ensue [244]. The impact and role of Western research in colonising Indigenous peoples and research has been well documented by Aboriginal and Torres Strait Islander academics and Indigenous academics from other colonised countries [1, 83, 131, 146, 174, 234, 235, 245-262]. Australia remains different in that it exists in a neo-colonialism environment with ongoing colonisation of First Nation peoples [131, 138]. Unlike countries such as India and Malaysia the colonisers never left Australia, and unlike New Zealand or Canada there have been no treaties with Australian Indigenous peoples, 'sovereignty never ceded' [131, 244, 263].

Colonisation has bestowed a dominant Western/eurocentric hegemony, through power, control, ownership, which has ensured that whiteness prevails in the research environments [174, 259, 262]. Whiteness is the 'invisible' privilege in which the 'dominant' culture is placed in an 'unnamed' but 'normative' position of power and privilege over minority cultures [131, 232, 264]. Through this process prevailing underlying assumptions ensure, that Western models of research and knowledge are the only way to "make sense of the world, of reality, of social life and of human beings" [259(p. 56)]. This dominant hegemony has created control and ownership, over research conduct and findings, which informs government, key stakeholders, policy and models of care [83, 229, 252, 255, 259, 262]. These Western research models have excluded Indigenous voice and knowledges, and importantly, also created circumstances where Aboriginal and Torres Strait Islander peoples are one of the most researched civilisations in the world, portrayed as a peoples, that 'needs fixing' [252, 259].

As an Aboriginal researcher and the first author, I find myself researching in a contested space, one which empowers and privileges Western scientific knowledge, particularly in quantitative research. As an Aboriginal person, I have lived experience of the oppressive nature that colonisation continues to have on Indigenous Knowledges and methodologies. Learning to become a researcher, was always going to be an intensely personal and challenging journey - a significantly important journey of sovereignty, resistance, and self-determination.

[i] Sovereignty is complex and encompassing for Aboriginal and Torres Strait Islander peoples. With core principles founded on our rights and responsibilities, it is connected to identity and our independence to determine our own destiny[285]

3.3.3 Research at the Interface

Conceptualised by Māori academic Sir Mason Durie, 'research at the interface' is the coming together of Indigenous Knowledges and methodologies with Western research methodologies [1, 260, 261]. At the interface these two knowledge systems entwine in equal partnerships, where one system is not superior over the other [260]. The interface, is an area of innovation and excitement, as it is here that additional new knowledge and methods arise in research, to fundamentally improve understanding in both knowledge systems [1, 260, 261]. The interface, as a concept for knowledge formation between two knowledge systems or world views, is significant globally, and has been captured in the literature in a range of forms.

For the Mi'kmaw First Nations people of Canada, the process of 'working at the interface' is explained through 'Two-eyed seeing' [265]. The process implies users are familiar with both knowledge systems, where one eye is focussed on Indigenous Knowledges and world views as connected to the land, and the other focussed on Western understandings of the world [265]. Through using both eyes to see the world an amalgamation occurs, similar to 'research at the interface' [266]. In the amalgamation process, the researcher is to weave back and forth between our worldviews, as it may be that the knowledge that one worldview provides is more suitable to the current circumstance or situation [265]. 'Research at the interface', has been described, as third space, by other non-Indigenous but oppressed scholars. The space where two different knowledge systems engage each other [264, 267, 268]. What arises from this engagement is the unique space of 'thirdness', which is the beginning of the narrative for change, encompassing justice, resilience and self-determination [267-269].

In Australia, Aboriginal and Torres Strait Islander scholars and communities have described learning, working and researching at the interface and its application in a range of ways. The 'cultural interface', between Indigenous and scientific knowledge, is the intersection of Western scientific methodology and our world view as Indigenous researchers, where we generate new stories, methodologies and approaches into Indigenous research methodology [257]. In these processes Western scientific methods of research are not refuted, but used to broaden our knowledge base, for we, as Indigenous researchers, can interrogate the results with a different lens to our non-Indigenous counterparts [256, 257, 260].

Ganma is a Yolŋo concept from Arnhem Land in the Northern Territory, similar to Nakata and Durie, in the coming together of two knowledge systems at a knowledge interface, Ganma is a

two-way sharing process between two different knowledge systems, where all knowledge is relational [268, 270].

> *"A river of water from the sea (Western knowledge), and a river of water from the land (Aboriginal knowledge) mutually engulf each other upon flowing into a common lagoon and becoming one.*
>
> *In coming together, the streams of water mix across the interface of the two currents and foam is created. This foam represents a new kind of knowledge. The forces of the stream combine and lead to deeper understanding and truth. Essentially, Ganma is a place where knowledge is (re)created".*
>
> Yunggirringa & Garnggulkpuy 2007; Kelly 2008, as cited in [270(p. 50)]

The creation of Ganma, takes more than two knowledge systems coming together. Just as Durie discusses in 'research at the interface', the Ganma process encompasses "mutual respect, shared benefits, human dignity and discovery" [1(p. 10), 271(p. 141)]. Similarly, Kaurna Elder Dr Lewis Kauwanu Yorloburka O'Brien, has spoken widely of "the meeting of salt and fresh water", as a metaphor for the Kaurna people of the Adelaide Plains in South Australia [272(p. 205)]. Like Ganma, it highlights the coming together of Aboriginal cultural knowledge as an essential system of knowledge in connection to Western knowledge systems [272].

The interface as a concept for knowledge (re)generation is apparent in central in-land Aboriginal communities as well. Murri[j] academic Wayne Williams has discussed similar concepts to the Ganma metaphor. For Murri communities, two knowledge systems, sand and red dirt come together [273]. In their coming together the two systems intertwine to create a new interface of knowledge [273]. Similarly, Murri academic Davis, has conceptualised Durithunga, a model for creating 'research at the interface'. Durithunga is an education model focussed on Indigenous leadership for embedding and integrating Indigenous Knowledges and research processes, from an Indigenous community perspective [246]. It interweaves Indigenous identity and strength and Migloo (non-Indigenous) educational spaces [246]. Durithunga focusses on Murri world views, central to Davis's identity, which encapsulate resilience, sovereignty, self-determination and empowerment of Indigenous identity [246].

[j] Murri, is the term used to Aboriginal communities and people from Queensland and Northern NSW.

Research concepts influence 'research at the interface'. Standpoint theory, focusses on the social location and situated knowledge of the researcher [274]. This information informs the researcher's standpoint and is used to design the theoretical framework, the lens, through which the research is approached [83]. Contemporary versions of Indigenous standpoint theory have been discussed by Nakata, Moreton-Robinson, Tur, Blanche, Wilson and Walter [83, 254, 275]. Specifically, Walter and Anderson pose it as an approach whereby researchers create their own research standpoint, which includes their social position, epistemology, ontology and axiology in Indigenous quantitative research [83]. In Indigenous quantitative research, these new approaches ensure the overall process for 'research at the interface' interrogates research outcomes in a different way, and seeks to undo an oppressive deficient model of discourse which clouds Indigenous quantitative research [83].

In working at the interface, Indigenist research is a concept which must be embraced. Developed by Aboriginal academic Irabinna Rigney, ground breaking in its development 20 years ago, this scholarship remains significantly relevant and important to the research environment. The concept of Indigenist research, can be used to unmask the racial nature of Western research processes and act to counterbalance this powerful dynamic of oppression, through decolonising Western research processes [252]. Indigenist research is informed by three fundamental and interconnected principles, "Resistance as the emancipatory imperative in Indigenist research", "Political Integrity in Indigenous research" and "Privileging Indigenous: voices in Indigenist research" [252(p. 116)]. These core principles acknowledge and engage with the knowledge of ongoing colonisation, oppression, transgenerational trauma and grief for Aboriginal and Torres Strait Islander communities [252]. In this research, the act of decolonising occurs creating self-determination and resilience, through empowering the research voice of Aboriginal and Torres Strait Islander peoples [174, 252].

3.3.4 Weaving a Methodology

"There is a whole ritual to weaving, and for me, it's a meditation".

Aunty Ellen Trevorrow,
Cultural Education and Awareness Centre
Camp Coorong [276(p. 44)]

For the first author, as an Aboriginal researcher, research being conducted at the knowledge interface, is an area where I must negotiate and prioritise the knowledge and values of two

different worldviews. In the coming together, and intertwining, of these worldviews, there is an exciting opportunity for innovation in research, which creates a new approach, encompassing Aboriginal ways of knowing, being, and doing, along with Western quantitative research approaches [1, 230]. Such an approach will enhance strength, self-determination and resilience to the research process ensuring outcomes are transparent, specifically for Aboriginal and Torres Strait Islander communities. Working at the interface needs careful thought, deliberation and reflection, as highlighted by the work of Rigney, Nakata, Durey, Smith, Davis and Doyle [1, 174, 246, 252, 253, 256, 257, 259-261]. For the first author, the concept of researching at the interface, creating my own interface and research standpoint, took me on a deep journey, connecting me back to my first memories of learning to basket weave (Table 7).

My Story
I learnt to weave when I was an academic at a staff development and bonding workshop, arranged by my then Aboriginal supervisor and mentor, Associate Professor Wendy Edmondson. I will admit that on this day I was concerned and apprehensive about attending the session, as there had been power dynamics at play at this workplace, which encompassed whiteness, racism, gender discrimination and lateral violence. As a young female Aboriginal academic at that time, I felt unsupported, disempowered and held high levels of scepticism and distrust. The workshop was held at Marra Dreaming, a cultural community centre in Northern Adelaide, South Australia. The centre uses art as a way of fostering social, emotional and spiritual well-being and healing. I remember the day my fingers touched the raffia: it felt as though something shifted inside me and the process of weaving was therapeutic and reflexive in nature. I felt connected to something that had always been a part of me, my soul, my essence, my identity, a deep voice and knowing inside me, but I had never done weaving before? How could this possibly be? Especially given I was terrible at sewing in home economics at school! Later in the workshop I noticed some of the Aunties who were teaching us giving a bit of a nod and raised an eyebrow to my weaving. I was told that I was a natural weaver apparently, as though I had been doing it my whole life. On this day I was approached to assist Marra Dreaming with teaching weaving workshops in the future when they were short on staff. My colleague and mentor at the end of the workshop said to me "Courtney, this process, your weaving, your ancestors are connecting and speaking to you". Little did I know the process which I had experienced - of revival, reconnection, resilience and self-determination through basket weaving - had been experienced by other Aboriginal women, and has been highlighted by the work of Carmichael [277].

Table 7: Learning to Basket Weave

3.3.5 Weaving

Weaving has long been a tradition of Aboriginal and Torres Strait Islander communities, and is an important skill in communities. Traditionally, fresh water rushes or reeds were collected

and dried, not only to create baskets but clothing, dilly bags[k], fishing nets, coolamons[l] and gathering tools [277]. There are various techniques to weaving, with the coiled stich most familiar to the first author, which is used to create a coiled basket [278]. Coiled baskets are created through a process in which a single plant base fibre (the coiled stitch) is wrapped around a foundational base of plant fibres, to provide strength, shape and durability of the structure [278]. This is the technique considered by the first author when weaving their methodology at the knowledge interface.

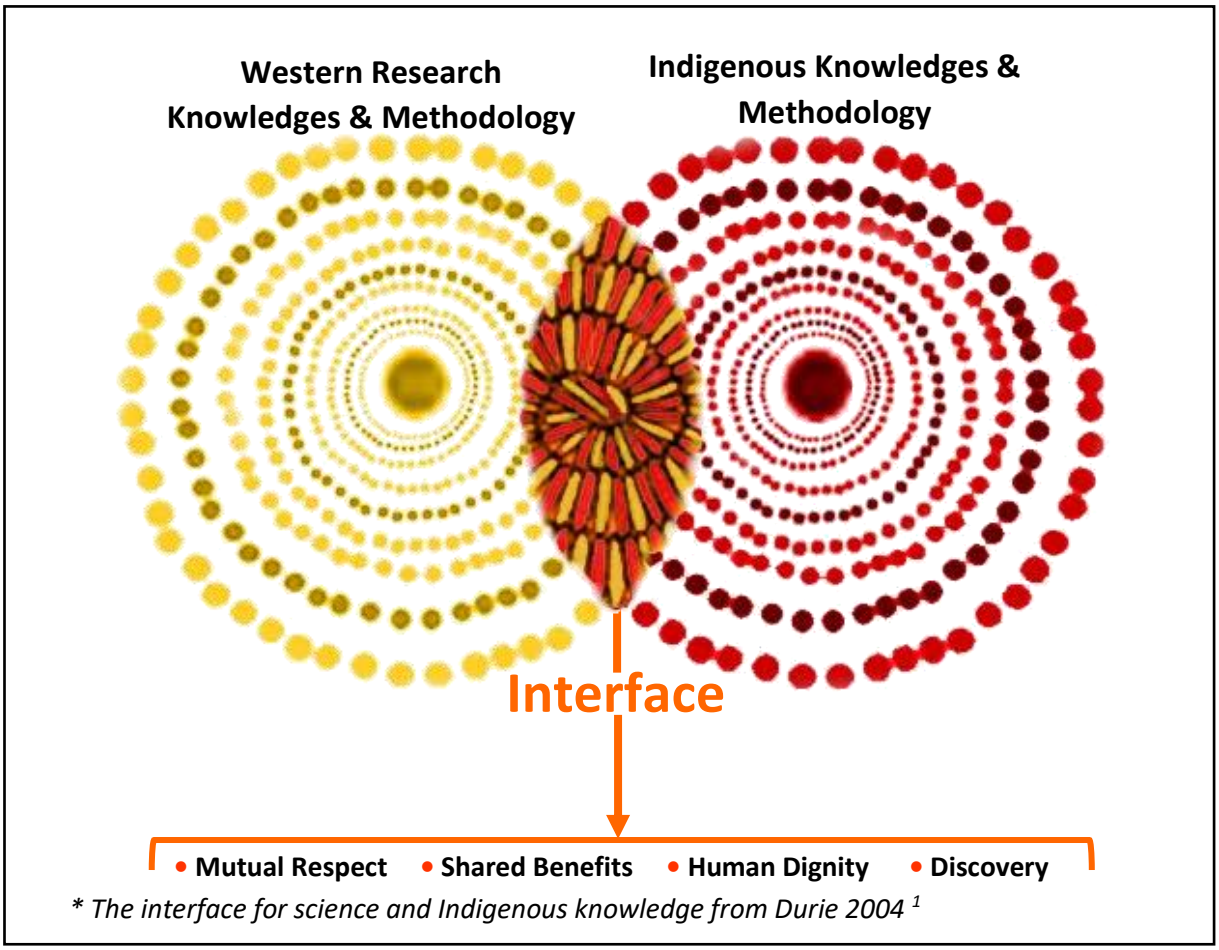


Figure 8: Weaving a research interface, weaving my research interface

A visual representation of weaving a research methodology at the interface (Figure 8) depicts two different communities of knowledge, represented as two different species of water rushes or reeds - one Native species from the land, the other an introduced species to the land (Table

[k] Dilly bags, common to Aboriginal and Torres Strait Islander communities across Australia, used to hold, store or carry belongings[253]

[l] Coolamon, common to Aboriginal and Torres Strait Islander communities across Australia, they are a curved bowl/dish used as a gathering/carrying tool, or to rock babies to sleep.

8). In this figure, the yellow circular structure depicts Western scientific knowledge systems and methodology, as an 'introduced species' (Table 8). Specifically, for the first author's research work this is quantitative research. The red circular structure depicts Indigenous Knowledges systems and methodology, these are systems which have been here from time immemorial, they are not 'stagnant', 'isolated' or even 'exotic', they continue to evolve and develop as time goes on [263]. Examples, in Table 9, of Aboriginal research methods include decolonisation and Yuri Ingarninthii.

Weaving a Methodology		
Knowledge System		**Weaving (Interface)**
Western (Yellow)	**Indigenous (Red)**	
Epistemology	Knowing	Selection of strands in weaving process
Axiology	Being	Stitching process in creating intersectional points
Ontology	Doing	Shape and structure through a process of intricate layering

Table 8: Concepts in the process of weaving a methodology.

Methodology	References	Definition
Decolonisation	253, 259, 279	Decolonisation requires researchers to recognise how colonisation has and continues to create research inequities in quantitative research, through often invisible and ingrained processes of whiteness.
Yuri Ingarninthii *"Enquiry with the ears, deep listening"*	175	Yuri Ingarninthii requires researchers to genuinely engage with the story (numbers) at hand ('*not only look')*, in a way, which respects and pays homage and resilience to Aboriginal and Torres Strait Islander Communities ('*record and understand*').
Nayri Kati – Good Numbers	83	Nayri Kati, a Palawa Tasmanian Aboriginal quantitative methodology, has two principles. 1. Indigenous lens to statistical data, 2. Decolonisation of the current western scientific hegemony over Indigenous statistics.
Indigenist Research	174, 252	Indigenist research uses past knowledge, to decolonise, create empowerment and resilience in the research space. It focusses on three principles. 1. Resistance as the emancipatory imperative in Indigenist research, 2. Political Integrity in Indigenous research, 3. Privileging Indigenous: voices in Indigenist research.

Table 9: Examples of Indigenous Research Methods Used as Coiled Stitch Textiles for Weaving a Methodology for 'Research at the Interface'.

When weaving a methodology for 'research at the interface', the two diverse knowledge systems and worldviews, Indigenous and Western, do not just sit over the top of each other and overlap, they intertwine, are weaved together, to ensure structural integrity (Figure 8,

Table 8). The coiled stitch technique, used to build the interface, draws from each knowledge system, Indigenous in red and Western in yellow. Each stitch contains significant knowledge from each diverse system, on ways of knowing and doing, including important research methods and approaches [280]. A process which allows the researcher to decide which knowledge system or methodology is needed to be weaved into creating rigour at the interface [83]. This process concerns Knowing (epistemology) for the interface, "...processes that allow expansion and contraction according to the social, political, historical and spatial dimensions …no one … Entity knows all, but each has sets of knowledge to fulfil particular roles" [230(p. 209)].

In the weaving technique, the coiled stitch, is wrapped and looped around a base structure of reeds, creating intersectional points. These intersectional points are representative of shared and respected knowledge, new discovery, and ways of understanding between Indigenous and Western knowledge systems [280]. These points reflect Being (axiology), the intrinsic and extrinsic values of knowledge systems, but in a framework of mutual understanding and respect, adapting where required to context change [83, 230]. These intersectional points of Being (axiology) are informed by our strands of Knowing (epistemology)[230]. The base structure (orange) represents new knowledge generation and creation between both knowledge systems. This base structure evolves through the dynamic and intricate layering of Indigenous and Western knowledge systems [280]. This process provides strength and structure for 'research at the interface', giving shared respect and responsibility to the research process, back to Aboriginal and Torres Strait Islander communities who are part of this research. It is also a process of Doing (ontology), in how the woven interface will approach and make sense of the research space and study, and as an Aboriginal researcher in quantitative research the process of decolonisation is significant here [83]. In this process our Doing (ontology) is created from our Being (axiology)[230].

There is a meaningful sharing aspect to the weaving process, weaving is often undertaken in larger family gatherings where knowledge and cultural teachings (i.e. language) are shared through yarning [276, 281]. This same process holds true for weaving a methodology for 'research at the interface', it is a time for learning, knowledge sharing, personal reflection and consideration. This is significantly important for this weaving process, this reflective nature is critical to the development of Knowing (epistemology), Being (axiology) and Doing (ontology) in the methodology for 'research at the interface'. This process occurs by drawing on key

Aboriginal and Torres Strait Islander scholars in the area of Indigenous Knowledges and research, and engaging with their 'teachings' through reflexivity [282]. Through this process, a 'rich' and 'powerful' methodology is created for 'research at the interface', visually vibrant and distinct from the two knowledge systems and worldviews. This strong and unique interface protects research outcomes, holding them safely and securely, in a way which provides the reciprocity and respect that Aboriginal and Torres Strait Islander communities deserve. This holds true to the core principles for 'research at the interface', "mutual respect, shared benefit, human dignity and discovery" [1, 261].

3.3.6 Weaving for Research at the Interface

As an Aboriginal researcher, weaving a methodology for 'research at the interface' in a predominantly quantitative research environment, is a challenge. After all this area has predominantly focussed on presenting deficit health statistics for Aboriginal and Torres Strait Islander children. In this section I will provide an example of how I have used weaving to design a methodology for 'research at the interface' and also examine a past deficit approach.

Burns remain a leading cause of mortality and disability in Australian children: national statistics demonstrate that Aboriginal and Torres Strait Islander children have higher rates of burns injury [52, 62, 283, 284]. The focus of my study is to provide a detailed analysis of burns injury in Australian children, to draw attention to burns inequities, helping to understand the contextual and clinical factors contributing to this. This included examining associations in patient hospital length of stay, as burns literature has reported an increased length of stay for Aboriginal and Torres Strait Islander children [284]. Presently, the majority of burns research focussed on Aboriginal and Torres Strait Islander patients, has been founded in Western quantitative research approaches. It is difficult to determine how this research adheres to basic recommendations of the National Health and Medical Research Council in Australia, for example core recommendations for the involvement of Aboriginal and Torres Strait Islander peoples in research governance projects [86, 87]. The risk of such approaches and lack of adherence to recommendations, is the reinforcement of deficit models of health and well-being for Aboriginal and Torres Strait Islander communities. This can result in enquiries, such as:

1. To compare burns burden between Indigenous and Australian children
2. Determine risk factors that increase the length of hospital stay in Indigenous children.

While burns research in Australian children has demonstrated there is higher incidence in Aboriginal and Torres Strait Islander children, 'burden' emphasis on Indigenous children places a 'problematic focus' on Indigenous children as the 'deficit Indigenous,' and does not try to understand the inequities present in the overall story. Problematic focusses are hard to shift once formed, they reinforce an individual's implicit bias and stereotyped attitudes towards Aboriginal and Torres Strait Islander peoples, as 'the cause of their poor status' [138, 144]. Indigenous children are separated from 'Australian children,' which is a common form of whiteness, placing non-Indigenous Australians in a position of power and as the 'unacknowledged norm' [83]. For the second question, past research has demonstrated hospital length of stay is greater for Aboriginal and Torres Strait Islander children [284]. However, this line of enquiry, places emphasis on being Indigenous, where 'Indigeneity' is focussed as a risk factor for increasing hospital length of stay. This is a deficit model of enquiry, it does not appreciate or comprehend how colonisation has created the circumstances which Aboriginal and Torres Strait Islander peoples continue to endure. There is no recognition for health inequities which Aboriginal and Torres Strait Islander people face. Inequities and circumstances which are continually reinforced by the ongoing process of colonisation in Australia. Colonisation, racism and whiteness have trained researchers to consider 'Indigeneity' as a risk factor, these ongoing processes (colonisation, racism and whiteness) have blinded researchers to the real truth. That truth being, that 'colonisation' is in actual fact the risk factor. In both questions, Indigenous Knowledges and voice are missing, clearly constructed from a colonial normative framework, underpinned by colonisation and further influenced by whiteness.

In my study, I centred strength based ideas in the narrative from the outset. A significant feature of this study over past research, was the prioritisation of Indigenous Knowledge from study formation through to data interpretation. For this, a retrospective study of data from the Burns Registry of Australian and New Zealand (BRANZ) was analysed from the October 2009 to July 2018. This registry is an epidemiological repository, monitoring burns incidence, causation and treatment in Australia. Established from non-Indigenous value systems, where the data set is focussed on recording Western clinical measures of burns injury. This is important when considering Being (axiology) for 'research at the interface', specifically in terms of which knowledge system holds knowledge power and how this can influence the research process.

Weaving the methodology for 'research at this interface', focussed on Indigenous research methods (outlined in Table 9) and quantitative research methods; these methods were used as the strands to weave the methodology for this interface. The quantitative research exploration used in this study of demographics, statistical significance and relatedness, were never used to define the methodology at the interface, only inform it, an important decolonisation process for this weaving this knowledge interface.

Decolonisation (Table 9) is a process which needs to occur at the outset of research enquiry, where the unacknowledged privilege and power held by Western knowledge systems, as related to colonisation, racism and whiteness, and depicted through 'power' and 'privilege' from one knowledge system (Western) over the other (Indigenous), must be acknowledged and shifted [144, 234, 252-254, 259, 266, 285]. Decolonisation allows all researchers to recognise and reflect, from the beginning on how colonisation continues to shape research agendas, which in-turn reinforce inequities [138, 279, 285]. For example in Aboriginal and Torres Strait Islander quantitative health research, colonisation has impacted on research enquiry, where often research questions are constructed through a colonial normative framework of deficit and whiteness, rather than strength and sovereignty, as outlined in the example above.

For the BRANZ study, Indigenous research methods of decolonisation, nayri kari and Indigenist research (Table 9) facilitated for formulation of the research questions:

1. Are burn injuries different for Aboriginal and Torres Strait Islander children?
2. Do inequities present in this epidemiological profile?
3. Do differences exist in hospital length of stay?
4. Is the hospital length of stay associated with health inequities, burn cause, severity and treatment?

Framing research questions in this way ensured the study was focussed on understanding burns inequities through a strength based process of enquiry and examination. The use of the selected Indigenous research methods, aims to resist the influence of colonisation, by not privileging Western knowledge and constructs, such as, prior assumptions surrounding burns in Aboriginal and Torres Strait Islander peoples and communities, such as assuming other Australian children were the unacknowledged norm, through to understanding that the data set is a Western constructed data repository [83, 144, 252, 253, 259, 279].

In this study, quantitative measures for data analyses, for instance descriptive statistics (means, standard deviations, and 95% confidence intervals), were used to provide an overview of paediatric burns injuries in Australia, covering patient demographics, burns and treatment characteristics. This included a stratified comparison across Aboriginal and Torres Strait Islander and Other Australian children. Statistical significance, through Pearson's Chi-Square, explored variable correlations for those variables included in the burns overview profiles [286]. A staged cox regression model explored the relatedness of variables to increased hospital length of stay [287]. In building this staged model, particularly variable selection, Indigenous Knowledges surrounding ways of knowing, being and doing, was an important focus over dominant Western constructs [83, 230]. For example, great caution was taken when selecting variables from the literature, in understanding that the knowledge surrounding these variables was constructed from a Western centric approach, focussed on privileging deficit constructs, where there was limited consideration of inequities.

Indigenous research methods were used to unpack and understand the outcomes from this statistical analyses. The method of Yuri Ingarninthii, a process of deep listening surrounding 'recording and understanding', was critical when examining results produced from the statistical analyses [175]. Particularly, Yuri Ingarninthii, is significant in understanding the narrative and context behind the numbers [175]. This process was enriched by Indigenist research and nayri kati, as firstly the research being conducted is by an Aboriginal researcher, supported by an Aboriginal supervisor and Aboriginal mentors. This process also utilised Aboriginal and Torres Strait Islander perspectives of health and well-being, and making sure they are central to interpreting research outcomes, and recognised the impact of comparing aggregated Aboriginal and Torres Strait Islander data to national burns data or Other Australian children, as the assumed 'normal' level [83].

I used 'Collaborative Yarning' with other Aboriginal researchers, and the first author's supervisors in this space, to unpack the narrative behind the study results [2, 251]. For example, I used collaboratively yarning to narratively enquire on inequity outcomes present in the results, in line with PROGRESS-Plus[m]. All of these research methods were important in weaving a strong and robust methodology for 'research at the interface', to hold the results from this

[m] PROGRESS-Plus: Place (residence), Race (ethnicity), Occupation, Gender, Religion, Education, Social-capital, Socioeconomic position, Age, Disability, Sexual Orientation, Other Vulnerable Groups[103]

study culturally safe and secure, and presenting them in a way which does not cause further harm or oppression to Aboriginal and Torres Strait Islander children.

3.3.6 Conclusion

Weaving a methodology for 'research at the interface' is a transformative process, powerful and reflexive, allowing researchers to conceptualise their research methodology in a different way, which privileges Aboriginal and Torres Strait Islander voices and knowledges. Through the weaving of a methodology, drawing from two diverse worldviews, innovation occurs, the creation of a methodology, akin to a coiled basket. The weaving process requires a central focus on mutual respect, benefit and cultural integrity for Aboriginal and Torres Strait Islander communities. So a respectful and culturally safe methodology for 'research at the interface' is structured, which enshrines honesty, ethical conduct for research processes, and protects the research outcomes, holding them safe and secure, in a way to benefit Aboriginal and Torres Strait Islander communities.

3.4 Part C: Textiles for the Woven Research Interfaces in this Thesis

In section 3.3.5 Ryder describes the coiled basket stitch that is used when weaving a research interface (Figure 9). This section will focus on the various textiles that Ryder uses to weave the research interfaces for studies in Chapter 2, Chapter 4, Chapter 5 and Chapter 7 in this thesis.

Figure 9: Coiled Stitch Basket by Courtney Ryder.

3.4.1 Indigenous Textiles (Red) - Indigenous Research Methods

The core Aboriginal research methodologies and methods which are drawn upon to inform the coiled stitch of the knowledge interface(s) in this thesis are conceptualised from a distinguished group of First Nations' researchers and academics globally. At my knowledge interface, textiles are used to create a strong and robust interface, highlighted in Figure 10.

Each textile contributing to the interface is outlined under the headings below, where each heading represents a textile but also a stitch in the interface.

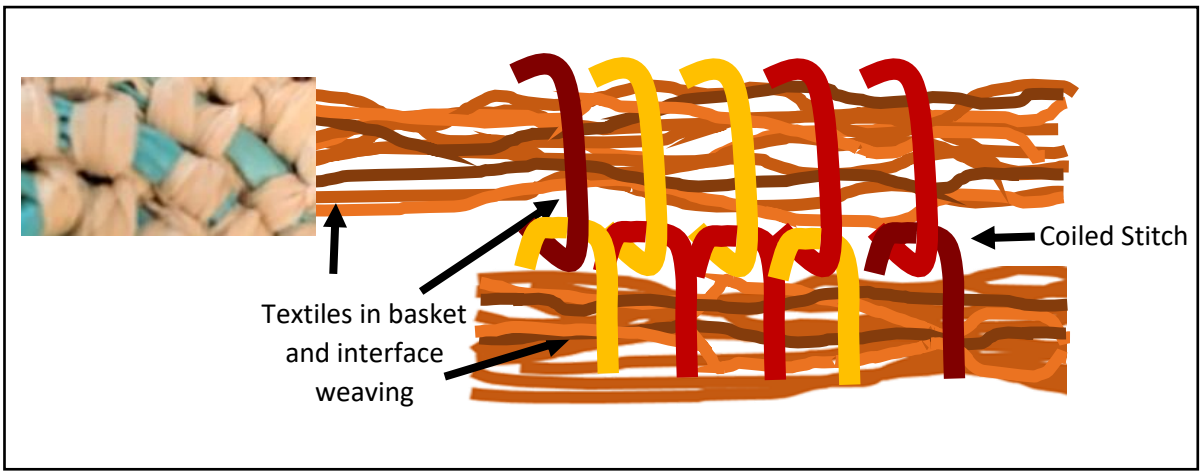


Figure 10: Coiled stitch process for part of a basket, highlighting coiled stitch textiles for creating the interface

3.4.1.1 Decolonisation

"Decolonisation is not a simple act, it is a journey that requires more than simple words and cannot be achieved in a short timeframe".

Sue Green[279(p. 262)] *Bindi Bennett*

Associate Professor Social Sciences, University of New South Wales, *Senior Lecturer Social Sciences University of Sunshine Coast*

Decolonisation is not about refuting Western knowledge or methodology, but rather encompasses the impact on Indigenous knowledge systems and the privilege held by Western knowledge systems. This is directly related to colonisation, racism and whiteness, and is depicted through 'power' and 'privilege' from one knowledge system (Western) over the other (Indigenous)[234, 252-254, 266, 288]. It is a process which allows researchers to recognise how colonisation has and continues to create health inequities, through often invisible and ingrained processes of whiteness [138, 279]. Decolonisation for Aboriginal researchers is a transformative and empowering process and includes resisting the influences of colonisation in the research process, while at the same time reclaiming research sovereignty through self-exploration and discovery, in which our own worldviews and perspectives become central to weaving our research interface [253, 279, 288]. Such practices include acknowledging Aboriginal and Torres Strait Islander perspectives of health and well-being and making sure they are central to the research process and the interpretation of outcomes [251]. Also through to recognising the impact of comparing aggregated Aboriginal and Torres Strait Islander data to national,

assumed 'normal' levels of health outcomes [83]. The process of decolonisation is central to weaving a research interface of strength and resilience to hold the research outcomes of the Coolamon study safely and securely.

3.4.1.2 Yuri Ingarninthii

> *"Yuri Ingarninthii, enquiry with the ears, deep Listening……*
> *Observation is to not only look at what you're seeing—you've got to record and understand what it is you're looking at".*
>
> *Dr Lewis Kauwanu Yerloburka O'Brien* [175(p. 460)]
> *Kaurna Elder*
> *Philosopher, Educator and Engineer*

Yuri Ingarninthii has been described by Kaurna Elder, Uncle Yerloburka as a method of deep listening in his work on the ARC project, Indigenous Knowledge: Water Sustainability and Wild Fire Mitigation. Although for this project, Yuri Ingarninthi was used in reference to fire management, it translates to "enquiry with the ears"[175(p. 460)], a form of deep listening - a Kaurna research method. Deep listening is a process which is greater than mindfully listening to an individual; it is a superior connection in which "voices from the land, spirit and people can be heard"[289(p. 13)], thus, seeking understanding and teachings from the whole environment [289]. The significance of Yuri Ingarninthii as a strand of the coiled stitch for this knowledge interface is that the majority of this thesis has been constructed on Kaurna country. As an Aboriginal researcher it is critical for me to acknowledge and pay respect to this connection.

The application of Yuri Ingarninthii requires Aboriginal researchers to explore, meaningfully and reflectively, whether the research process (methods, analyses and outcomes) are structured in a way that facilitates oppression-enforcing colonisation or are liberating - enhancing the resilience and self-determination of Aboriginal and Torres Strait Islander communities [252]. It requires Aboriginal researchers to truly engage with the story at hand ("not only look") in a way which pays respect and homage to Aboriginal and Torres Strait Islander communities ("record and understand")[175(p.460)]. As an Aboriginal researcher I must understand our families; how quantitative tools or measures interrogate our families, and in this interrogation, seek to truly identify, understand and reflect on what these tools are asking and telling us, as well as what are they are not telling us about burns injuries in Aboriginal and Torres Strait Islander families.

Working in the quantitative space as an Aboriginal researcher has its challenges, in not just being caught up in the output of our analyses, the 'numbers'. Often, these numbers may only capture the surface, or superficial layer of the whole story. For instance, the literature has demonstrated that in New South Wales, Aboriginal and Torres Strait Islander children have longer lengths of stays in hospital than other Australian children [290]. While this is an important and clear health inequity, as an Aboriginal researcher I need to think broadly, deeper than just the surface level. This requires understanding the context of an individual's life and the impact of the social determinants of health and colonisation in Australia. For instance, considering the longer LOS for Aboriginal and Torres Strait Islander children with a burns injury, factors for families include:

- come from lower SES backgrounds
- live in outer regional areas of Australia
- Experience greater burn complexity (depth, wound infection)
- live through ongoing colonisation
- face further marginalisation through racism and whiteness.

These factors must be considered in the context of their family and community as well. These factors are also critical for reporting and communicating outcomes. This process should focus on rejecting deficit-based reporting, rather, reflecting a process of resilience and self-determination, holding integrity and respect for the families who were part of the research process. This approach is informed by, and reflects the work of, Aboriginal researcher Maggie Walter with her Indigenous methodology, Nayri Kati – good numbers [83].

3.4.1.3 Nayri Kati – Good Numbers

Nayri kati translates to 'good numbers' from the Palawa Tasmanian Aboriginal Language [83]. Nayri kati is an Indigenous quantitative methodology developed from the stand point of Professor Maggie Walter and her engagement in the quantitative research space [83]. Nayri kati is one of very few published Indigenous quantitative methodologies, demonstrating the resilience and strength of Walter's work, specifically in terms of initiating and innovating Indigenous methodologies in quantitative research. For this reason, the entire nayri kati methodology will not be weaved into my research interface; however, the important fundamentals and teachings from nayri kati will be included. There are two fundamental principles to the nayri kati methodology, which will be woven into my research interface [83]:

1. Indigenous lens to statistical data
    a. Indigenous knowledge systems, voices and teachings are privileged

b. Western scientific value systems are not the unacknowledged norm

c. No presumed starting point of an Indigenous deficit

2. Decolonisation of the current Western scientific hegemony of Indigenous statistics.

3.4.1.4 Indigenist Research

"Indigenous Intellectual sovereignty means moving toward a cultural criticism that is embedded in the Indigenous Australian experience, and that is influenced by the intellectual work we do as scholars for the social, political, economic and cultural struggle of Indigenous Australians".

Lester Irabinna Rigney [174(p. 10)]
Professor of Education
University of South Australia

The significance of Indigenist research at the interface was discussed earlier. The three principles of Indigenist research are fundamental strands to my research interface, for strengthening the resilience and self-determination of the research interface. While these principles overlap with the nayri kati methodology, this is important in defining a research interface which privileges the voices and knowledge of Aboriginal and Torres Strait Islander peoples [174]. A body of knowledge which encompasses identity along with the ongoing experiences of colonisation, one which does not focus on Western constructs and knowledge of Aboriginal and Torres Strait Islander peoples and communities, where Western scientific knowledge is not seen as the unacknowledged norm [83, 174, 291]. This is the significance of using Indigenist research as a strand for weaving this interface, in that the voice of Aboriginal and Torres Strait Islander families from the Coolamon study are identifiable in the research outcomes.

3.4.1.5 Yarning

"Story telling is a feature of Indigenous societies where oral traditions were the main form of transmitting and sharing knowledge with individuals and between groups".

Professor Dawn Bessarab [2(p. 38)]
Director of the Centre for Aboriginal Medical and Dental Health,
University of Western Australia

Dr Bridget Ng'andu
Lecturer in Social Work
University of Kent

Yarning is an Indigenous research method, often described as an "Indigenous form of conversational" [2(p. 37), 292]. In this research space, yarning is a "process and exchange", following a prescribed protocol, which establishes rationality and anticipated outcomes which determines accountability [292(p. 3)]. Bessarab (2010) outlines four different yarning approaches which assist in the yarning process for research (Figure 11). This process, research topic yarning, is the strand which makes up the coiled stitch for my research interface [2, 292]. Research topic yarning has been described as a narrative form of enquiry, however it is a very different process to general quantitative research collection through semi-structured interviews; rather it is a "conversation with a purpose" [2(p. 40), 293].

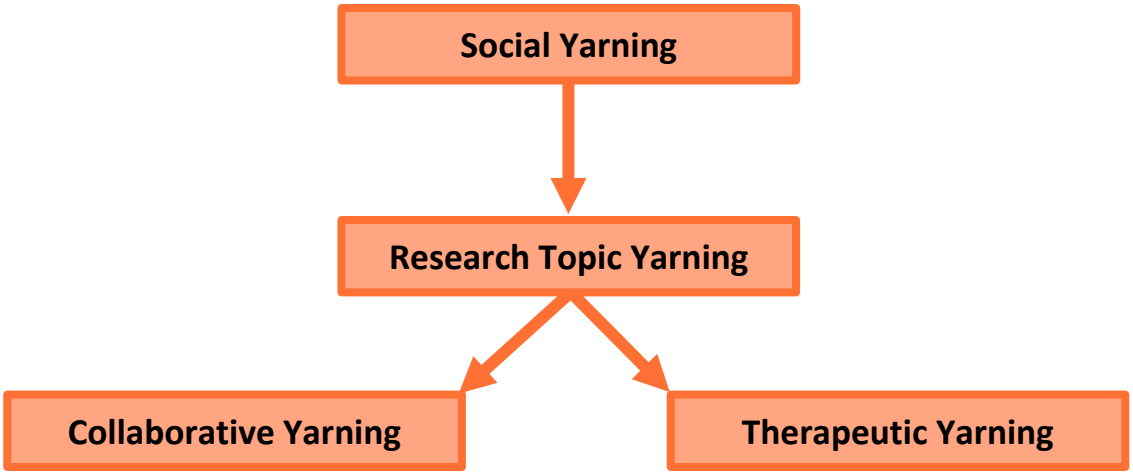


Figure 11: The process of research yarning, as described by Bessarab and Ng'andu [2(p. 40)]

Yarning is a journey for both the researcher and participant(s). It follows a unique enquiry process, one which does not follow direct questioning [2, 292-294]. In this process there is emphasis and accountability of the researcher to establish an environment of equity, a place where power dynamics do not exist [292-294]. It also requires the researcher to engage with Yarning participants on a very different level, utilising skills of cultural safety, in which an equal partnership to the research yarning process is established [2, 293, 294]. Establishing this relationship is critical so that all participants in the Yarn feel safe and respected in their contributions and it also allows the yarn to unfold as yarning is not a static direct process [2, 293].

While described as a conversational method, the yarning process is much more elaborate than a conversation. The yarning must be undertaken respectfully and reflect the accountability which has been established between the Aboriginal and Torres Strait Islander participants and researcher. Critical to this process is reflection which leads to reflexivity. This is important for

knowledge application when drawing on the main themes from the Yarn, which can be described as the gathered Aboriginal knowledge and teachings. Yarning as a strand in this research interface is imperative in informing the way in which mixed methods research is undertaken, but also for the interpretation and accountability of the research outcomes in this process.

3.4.2 Western Textiles (Yellow)

The Western research methodologies which are used to inform the research interface of this thesis are highlighted under the key headings and in Table 10 below. As described earlier, Western research knowledge is not refuted, but rather used to broaden our knowledge base and understanding as Aboriginal researchers at the research interface [1, 257].

3.4.2.1 Reflexivity

> *"reflexivity as a process by which researchers notice their responses to people, events and the world around them and use that knowledge to inform their actions, communications and understandings".*
>
> *Annabelle Wilson[282(p. 220)]*
> *Senior Researcher*
> *College of Medicine and Public Health*
> *Flinders University*

Reflexivity is a transformative process for researchers, a process whereby researchers continually critically reflect their position and context in the work that they do and engage in a process of enhancement and modification by acting on these reflective points. It is an important strand of this research interface as it allows me as an Aboriginal researcher to continually refocus and consider my position in this research journey. It also allows me to continually engage with the commitment I have to the Aboriginal and Torres Strait Islander families, in terms of producing research and outcomes which will be of benefit to the community. Wilson, although a non-Aboriginal researcher, provides a useful framework of reflexivity which she engaged with for her doctoral studies [282]. While my world view and experience are uniquely different as an Aboriginal researcher to Wilson, she provides a framework with elements that any researcher working in Aboriginal and Torres Strait Islander health can engage with. Significant parts of this framework which are critical to this research interface include [282]:

1. Uncertainty and angst
2. Relationships
3. Reciprocity
4. Transparency
5. Trust

3.4.2.2 Equity Lens

> *"Health equity is defined as the absence of discriminatory or avoidable disparities in health".*
>
> Courtney Ryder [103(p. 2)]

Research central to the social determinants of Indigenous health and social gradient of health focussing on targeting health inequities and breaking the cycle of poverty has become an important agenda item, nationally and internationally [105]. In injury specifically, a clear socio-economic gradient exists, as highlighted in Chapter 2. A radical change is needed in this research space, where these inequities are clearly articulated[103]. Chapter 4 highlights the specific overrepresentation of Aboriginal and Torres Strait Islander children with burns injuries. Despite the need and obvious priority, Aboriginal and Torres Strait Islander health research is often conducted without the active involvement of Aboriginal researchers and communities. These practices reinforce a Western research epistemology, analysis and dissemination of study results, often resulting in interventions or analyses which reinforce inequities [105, 146, 174, 295]. For research with Australian Aboriginal people to warrant any relevance and benefit to their communities a decolonised research process which involves the community must ensue [146]. There are a range of institutes across Australia actively working to change practice in Aboriginal and Torres Strait Islander health research through:

- Including Aboriginal and Torres Strait Islander chief investigators for the grants
- The Employment of Aboriginal and Torres Strait Islander researchers
- Scholarships and support for Aboriginal and Torres Strait Islander students for higher degrees.

These processes, along with engaging in best practice in Aboriginal and Torres Strait Islander research, have enhanced overall study objectives, design and outcomes. Some of these projects include The Lililwan Project, Driving Change and The Ironbark Project.

A weaving thread encapsulating equity was significant for weaving this research interface. Key equity measures of PROGRESS-Plus and the Nasser equity lens were used to focus research agendas for the studies in this thesis on priority setting and outcome evaluation in equity, specific for Aboriginal and Torres Strait Islander communities [182]. These processes were also used as a point of reflection and reflexivity in data collection, assessment and interpretation, and the dissemination of outcomes.

3.4.2.3 Quantitative Research Methods

Quantitative research encompasses a broad range of research methods and methodologies. The Coolamon study, from where these data are derived, includes (along with rich qualitative data) a prospective cohort study in which a range of quantifiable measures are being used to capture Aboriginal and Torres Strait Islander patient and family data over a two-year period. The aspects of quantitative methods used in the studies for this thesis very much address the statistical relationship between variables which are drawn from quantifiable measures [296]. However, the way in which I interpret how these variables interact is critically important. While these quantitative methods are an essential part of the coiled stitch which produces my research interface, they do not define the research interface, but serve only to inform it. The core quantitative methods drawn upon to inform the coiled stitch of this research interface are highlighted in Table 10.

Descriptive Statistics			
Test/Process		Reference	Description
	Means Mediums standard deviations inter-quartile ranges 95% confidence intervals	287, 297	Descriptive statistics are techniques for describing and presenting a data set drawn from a specific population.
Statistical Significance			
	Pearson's Chi-Square (χ^2)	286	Statistical measure for hypothesis testing for the significance of difference, and categories which account for this difference.
Statistical Correlations and Modelling			
	Cox Regression	287	Correlation is a statistical method used to examine the extent and direction (positive/negative) of relatedness of two or more variables.

	Logistic Regression	298	Process used to examine and predict the relationship between dependent and independent variables.
Missing Data Processes			
	Multivariate Imputation using Chained Equations	299	Imputation process for supplementing variables in data sets with missing –values.
	Predictive Mean Matching	299	Process used in imputations analyses, where missing values are supplemented through matching of similar variables. These values are then used to average a supplemented value.
Psychometric Property Assessment			
Validity			
	Face	300	The relevance and readability of the instrument for the target population.
	Content • Content Validity Index	301-303	The ability of the instrument in capturing latent variables/main constructs.
	Construct • Exploratory Factor Analysis	303-305	The extent to which the measurement accomplishes the purpose for which it is intended. The relationship between the latent variable and construct of interest.
Reliability			
	Internal Consistency • Cronbach's Alpha	306	The relatedness of items in instruments to each other in measuring main constructs.
	Repeatability • Interclass Correlation Coefficient	307, 308	The ability of instrument scores to be reproduced by the same users over a set period where conditions have not changed, through test re-test process.

Table 10: Quantitative research methods/processes used in studies for chapters (2,4,5,7).

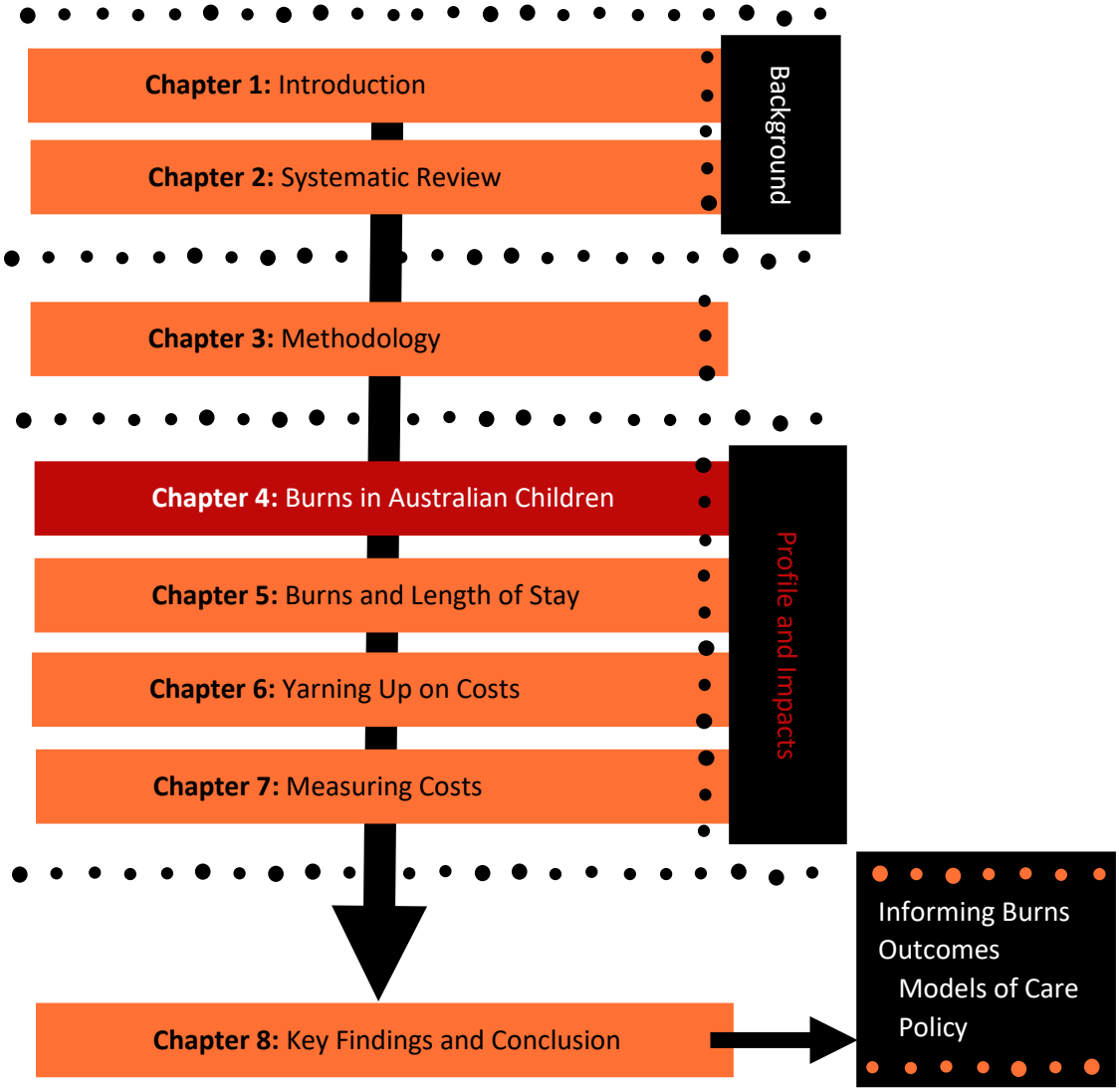
3.5 Methodology Summary

This chapter has outlined the rationale and significance of using Indigenous research methodologies when engaging in health research with Aboriginal and Torres Strait Islander communities. The foundation from which this methodology is established, deconstruction and poststructuralism, has been outlined. The overall methodology has been conceptualised through research at the interface, where two different systems of knowledge and research, Indigenous and Western, come together for the overall benefit of Aboriginal and Torres Strait Islander health research. The standpoint of the Aboriginal researcher is theorised through interface weaving, a process used to create the research interface in this thesis. Interface weaving is akin to creating a coiled basket, which will hold research outcomes safe, securely and with the integrity that all Aboriginal and Torres Strait Islander communities should be afforded. Detailed definitions are provided for the Indigenous and Western textiles (research

methods) used for weaving at the interface. These textiles are the research methods selected for each of the studies which form a part of this thesis. At the beginning of each study (Chapter 2, 4, 5, & 7) a section on the methodology – weaving a research interface - will be presented so it is clear as to how research at the interface has been used to inform each study.

CHAPTER 4

Burn Injuries in Hospitalised Aboriginal and Torres Strait Islander Children - An Epidemiological Profile



4.1 Preamble

This study was conducted to understand the overall epidemiological profile of burns in Australian children with a specific focus on Aboriginal and Torres Strait Islander children. In understanding the inequities present in this profile and unpacking health inequity manifestations, risk factors were examined around bacterial infection in Aboriginal and Torres Strait Islander children and other Australian children.

This study was important in understanding and describing health inequities in burns for Aboriginal and Torres Strait Islander children using a national epidemiological data repository. Using bacterial infection as a focus, the study demonstrated how health inequities are present and contribute to ongoing health and well-being impacts for Aboriginal and Torres Strait Islander families. The outcomes from this study were used to inform Chapter 5 and contribute to recommendations in Chapter 7.

This chapter has been published in:

Ryder, C., Mackean, C., Hunter, K., Rogers, K., Holland, A. J.A., and Ivers, R., Burn Injuries in Hospitalised Australian Children - An Epidemiological Profile. Journal of Burns Care and Research. 2020. (Epub ahead of print).

Corresponding Author: Courtney Ryder

Published: 10 September 2020

4.1.1 Summary: Weaving the Interface

> *"Problematic constructions of Indigenous peoples, as the sole cause of their poor status, have been replicated through the decades since invasion".*
>
> Juanita Sherwood [144(p. 29)]

National registry data, big data, are national data sets used to construct overall epidemiological profiles of different populations. In Australia, the epidemiological profile of burns in children, especially Aboriginal and Torres Strait Islander children, is based on a strong foundational structure of hegemony - Western quantitative research. As such, they do not conform to Indigenous Data Sovereignty principles, in part because the majority were established prior to obtaining a full appreciation and understanding of Indigenous Data Sovereignty. However, this has significant impact on the way in which data surrounding Aboriginal and Torres Strait Islander patients has been selected, analysed, engaged with and understood. As outlined in Chapter 3, Western quantitative research methodology contains

knowledge which has and is used to colonise Australia, a process that continues to dehumanise and medicalise Aboriginal and Torres Strait Islander peoples [83, 144, 309]. For children, this is a process which goes against the UN Convention on the Rights of the Child, and for Australia's First Nations peoples it goes against the UN Declaration on the Rights of Indigenous Peoples [181, 310]. Furthermore, it does not support the NHMRC guidelines for working with Aboriginal and Torres Strait Islander communities [86, 87].

The BRANZ is the registry that this study is focussed on and contains data on Aboriginal and Torres Strait Islander children. To date, the majority of data in the BRANZ has focussed on Australian children which may contain some analyses on Aboriginal and Torres Strait Islander children and has been analysed in two different ways, as is generally the case with hospital patients:

1. Whole of cohort analyses
2. General distribution stratification [51-53, 62, 66].

In these processes, the first neglects trying to understand health impacts facing Aboriginal and Torres Strait Islander children by 'treating all children statistically the same' and in the second, researchers fall into the trap of comparing data outputs from Aboriginal and Torres Strait Islander children to other Australian children, where other Australian children are the 'unacknowledged norm' [83]. Furthermore, where more complex statistical analyses are undertaken, generally they are not stratified; Aboriginal and Torres Strait Islander children are 'statistically the same' again [52, 68]. In other circumstances, when these analyses are stratified, a 'medicalisation' comparison occurs, an 'othering' process creating "problematic constructions" of Aboriginal and Torres Strait Islander children and their families as the only cause of their poor health status [144]. Little focus is given on understanding the health inequities (ie living remotely, colonisation) which are at interplay and shape the health circumstances (ie longer hospital stays) and inequity manifestations (ie significant cost to family).

These are all practices which do not draw upon Indigenous Knowledge or methodologies, they do not act in strength-based ways and can cause further harm to Aboriginal and Torres Strait Islander children through enforced negative narratives. To reduce the risk of problematic constructions disempowering outcome analyses, knowledge interface and decolonisation methodologies were drawn upon for the weaving approach in the study, using the process outlined in Chapter 3 and illustrated in Figure 12. There are five main sections which make up the woven interface of this study.

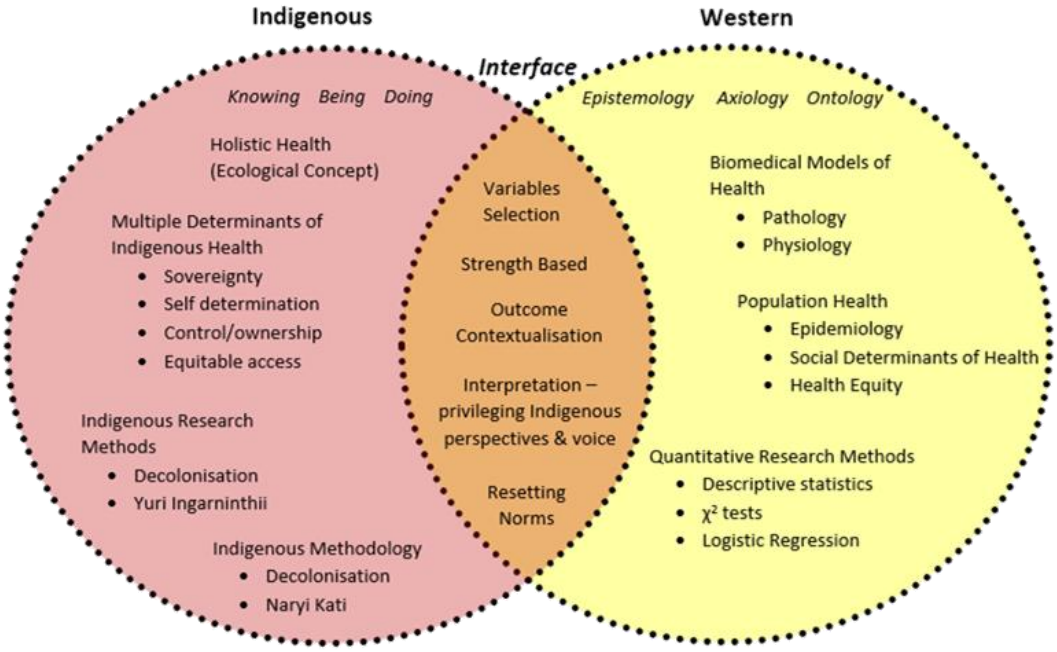


Figure 12: Visual representation of research at this knowledge interface Chapter 4.

Variable Selection

This section drew on Indigenous Knowledge of the multiple determinants of Indigenous health: holistic health, Indigenous research methods (processes of decolonisation), population health (epidemiology, social determinants of health equity – PROGRESS-Plus) and biomedical models of health (the BRANZ – burns pathology, bacterial infection) to select variables for analysis. The focus for variable selection was placed on contextualising health inequities and multiple determinants in the overall epidemiological profile of the BRANZ. Early analyses, to gain an appreciation of the BRANZ data, identified higher incidences of *Staphylococcus sp*. and *Streptococcus sp.* infections in Aboriginal and Torres Strait Islander children where it was decided to focus on odds ratios surrounding this infection, again to highlight the health inequities impacting Aboriginal and Torres Strait Islander children.

Strength Based

Burns research literature and BRANZ annual reports have identified that Aboriginal and Torres Strait Islander children experience a higher incidence of burn injury [51, 53, 62, 63, 66]. As outlined above, this research has predominantly focussed on Western knowledge systems, for example the use of quantitative research measures (descriptive statistics, logistic regression), with research outputs contextualised by population health (epidemiology, social determinants of health, health inequities). While these knowledge systems are important, it was imperative

that Indigenous Knowledges focussed on holistic health, multiple determinants along with decolonising methods to create a strength based approach from the study outset. Starting these processes from the outset ensured on focussing research enquiry away from a standard epidemiological approach to one that encompassed Western knowledge of health inequities, the social determinants of health, Indigenous Knowledge of holistic health, as well as the multiple determinants of Indigenous health. In this process decolonising practices were employed to strengthen the enquiry base.

Outcome Contextualisation

In this section, Indigenous Knowledge of the multiple determinants of health, holistic health, Indigenous research methods (Yuri Ingarninthii, decolonisation) and Indigenous methodologies (nayri kari) were used with Western knowledge of population health (burns epidemiology, social determinants of health, health inequities) and quantitative research methods (descriptive statistics, χ^2 tests and logistic regression). Nayri kari, along with population health knowledge, was used to explore the equity outcomes from analyses between groups. For instance, while 'very low' to 'low' SES was common for Australian children hospitalised for a burns injury, Aboriginal and Torres Strait Islander families are always at the most disadvantaged across any socio-economic indicator [83]. This, along with exclusion from other economic opportunities and resources, are processes of ongoing colonisation and highlight the transgenerational impacts [83]. This is a different way of contextualising the outcomes from this research, as past research has focussed on placing focus on the individual (victim-blaming)[84]. Decolonisation processes, drawing on poststructuralism concepts, was also important in understanding the outcomes from the demographic statistics and logistic regression. This was used when comparing results from Aboriginal and Torres Strait Islander children with other Australian children. The differences between Aboriginal and Torres Strait Islander children and other Australian children in these analyses represented significant health inequities, transgenerational inequities created from colonisation which continue to marginalise Australia's First peoples [144]. To contextualise these outcomes research topic yarning was employed with my supervisors. In these yarning sessions focus was given on considering the multiple determinants of health, holistic health, population health knowledge (social determinants of health and health inequities) in the overall outputs from the quantitative research knowledge. This was an important part of engaging in Yuri Ingarninthii processes, to not only contextualise outputs, but to further engage with Aboriginal and Torres Strait Islander stories behind the numbers.

Interpretation – Privileging Indigenous Perspectives and Voice

The lived experiences of student, Courtney Ryder and supervisor, Associate Professor Tamara Mackean, were important for focussing on Indigenous Knowledge (knowing, being and doing), and informed the study design from variable selection, statistical analyses to the interpretation of results at the knowledge interface for this study. To ensure Indigenous perspectives and voices were privileged, concepts from the Indigenous methodology, Naryi Kati were drawn upon. A key process for Naryi Kati methodology is a repositioning of quantitative research with an Indigenous lens so that other Australian children are not considered to be the unacknowledged norm (also important for 'Resetting Norms')[83]. In this study, this repositioning occurred with an equity focus (as defined by PROGRESS-Plus) to define variables for both the descriptive statistics and logistic regression models.

Decolonising actions were also employed to further focus on Aboriginal and Torres Strait Islander perspectives and voice. Decolonisation actions included, where possible, referencing First Nations studies, First Nations authors, or referencing studies which had been undertaken *with* Aboriginal and Torres Strait Islander communities, as opposed to 'on'. This decolonisation action assists in contextualising outcomes, but also by connecting with Yuri Ingarninthii processes, or the data narrative. Other decolonisation actions included reflecting on the limitations of the BRANZ. The BRANZ is a Western epidemiological data repository which does not conform to Indigenous Data Sovereignty. The BRANZ inception predates concepts of Indigenous Data Sovereignty and as such it does not include First Nations knowledge or constructions. This must be considered when selecting variables for analysis or creating new variables and is especially true when new variables are created from other databases which also may not conform to Indigenous Data Sovereignty, ie Accessibility/Remoteness Index of Australia – ARIA or Socio-Economic Indexes for Area – SEIFA. The limitations of this must be considered, as well as the impact that this may have on Aboriginal and Torres Strait Islander data.

Resetting Norms

In this process, Indigenous Knowledge of holistic health, multiple determinants of Indigenous health, Indigenous research methodologies (Nayri Kari and decolonisation) and Western knowledge from quantitative research outputs and health equity were used. Yuri Ingarninthii processes were used in the consideration and reflection of statistical analysis models. Yuri

Ingarninthii, as a process, required not only engaging with the stories of Aboriginal and Torres Strait Islander families, but understanding that these numbers were drawn from the BRANZ as a Western constructed data repository. This required reflectively considering how the quantitative tools and measures in this analysis were limited in their exploration. They are only capturing one area of a larger story, and by doing so the Aboriginal and Torres Strait Islander patient's and family's experience is diminished. Factors of racism, whiteness and ongoing colonisation during the treatment of the burns injury is not captured in these analyses or exploration. With this in mind, it was imperative to ensure that the over-medicalisation of Aboriginal and Torres Strait Islander children did not transpire, for instance, with consideration to the higher incidences of Streptococcal sp. infections [309].

Resetting norms also included using quantitative research outputs, health inequities, the multiple determinants of Indigenous health and holistic health knowledge with processes of decolonisation for reporting; for instance, in identifying and recognising that the higher incidence of 'low to very low SES' in Aboriginal and Torres Strait Islander children with a burns injury is a manifestation of ongoing colonisation in Australia [84]. Also, having data stratified for Aboriginal and Torres Strait Islander children and other Australian children is a decolonising action which uses Nayri Kati processes. It allows for the focus to be on Aboriginal and Torres Strait Islander children, where comparisons occur only to highlight the health inequities present or the differing outcomes between groups, such as the incidence of flame burns by fire as compared to friction burns by treadmill in both groups. These practices move away from a 'sameness' model in which all children are treated the same and move away from an 'Indigenous deficit standpoint' where other Australian children are not 'the unacknowledged norm' [83, 84, 144, 311]

It was also imperative to try to reset the data narrative in this area by considering the limitations in burns injury literature for Aboriginal and Torres Strait Islander children. Currently the majority of this research has been conducted in New South Wales from linked hospital data. In these cases it was important to use data narratives which have been undertaken with Aboriginal and Torres Strait Islander children, from studies which conform to Indigenous Data Sovereignty, such as the Footprints in Time [10, 77, 78, 312, 313].

ARE WE AT THE INTERFACE?

There are four important principles that determine if research is at the interface.

Mutual Respect

Both knowledge systems, Indigenous and Western, were used in conjunction over the five sections of the interface for this study. The strengths of each system were used at the knowledge interface to ensure the research outcomes were met. Principles for research at the knowledge interface require that knowledge of both systems is acknowledged and given the space that it requires for effective collaboration [1].

Shared Benefits

Being at the knowledge interface requires a shared benefit for both knowledge systems [1]. Western knowledge systems benefit from this work by contributing to the academic discourse, but also in this is a shift in applying an Indigenous lens to this academic discourse. For Indigenous Knowledge, the benefit is placed in reshaping the overall research approach in this area, moving away from the normative colonial framework which plagues quantitative research spaces. In doing this, research outcomes have meaning and are representative of Indigenous Knowledge for Aboriginal and Torres Strait Islander communities. It is these approaches and knowledge that move towards processes of Indigenous data sovereignty and will have traction for reshaping the way that government and stakeholder bodies engage in this space.

Human Dignity

Part of mutual respect is about allowing both knowledge systems the space, so that collaboration can occur effectively [1]. For both knowledge systems to be able to collaborate, there must be human dignity for each knowledge system. This can be seen through the space provided for quantitative research methods, and then in providing space for the use of multiple determinants of health and decolonisation processes to contextualise outcomes at this knowledge interface. In this process, each knowledge system comes together and intertwines in equal partnerships, where one knowledge system is not treated as superior over the other [1, 261].

Discovery

Each of the five sections of this knowledge interface contains 'discovery' from the collaboration of both knowledge systems. From variable selection, by exploring ways to select variables based on the multiple determinants of health and biomedical models of health for burns through to resetting norms, which start with stratified data for Aboriginal and Torres

Strait Islander children and other Australian children, allowing for discovery in the data set away from an 'Indigenous deficit' approach [83]. Each section is important in the discovery of a new approach and understanding of the epidemiological burns profile in Aboriginal and Torres Strait Islander children. It is this discovery which provides new information to the academic landscape, encompassing Indigenous Knowledge, to allow a different discourse to ensue in the future.

> *"An understanding of context is essential to the Indigenous health stories that are written today".*
>
> Juanita Sherwood p. 29 [144(p. 29)]

4.2 Abstract

Background: Globally, First Nations children sustain burns at a higher rate than other children. Little is understood about how health inequities contribute to this, especially from an Indigenous viewpoint.

Methods: We analysed data from the BRANZ for acute burns in children (<16 years) admitted to hospital between October 2009 and July 2018. Descriptive statistics examined equity variables in patient and injury characteristics. Poisson regression was used to describe factors associated with bacterial infection. Indigenous research methods were used throughout.

Results: Aboriginal and Torres Strait Islander children represented 10.4% of the study population. Health inequities were present in Aboriginal and Torres Strait Islander children with longer hospital LOS (9.5 vs 4.6 days), rural residency (61.3% vs 13.9%), lower SES (72.2% vs 34.9%) and more flame burns (19.5% vs 10.6%) compared to other Australian children. *Streptococcus sp.* infection risk was four times greater in Aboriginal and Torres Strait Islander children compared to other Australian children. Flame burns and high %TBSA burns were a risk for *Staphylococcus sp.* and *Streptococcus sp.* infection in all children.

Conclusion: The epidemiological profile for burns injuries managed in Australian burns centres differs between Aboriginal and Torres Strait Islander children and other children, indicating persistent health inequities. These differences should be considered in the development of injury prevention strategies and the clinical management of burns injuries in First Nations children and their families.

4.3 Introduction

Globally, burns are a leading cause of mortality and morbidity in children [30, 35, 51, 314]. In high income countries, such as American, Australia, and Canada, burns are one of the leading causes of mortality for unintentional injury in children with similar profiles: male, less than 5 years of age, and a predominance of scald burns [35, 36, 45, 51, 315]. Health inequities, including the presence of avoidable or discriminatory health disparities, remain prevalent [103-105]. Inequity indicators, such as low socioeconomic status (SES) and residential remoteness, influence both burn incidence and severity. Furthermore, these inequities are greatest in children from minority backgrounds [36, 49, 63, 314, 316]. Recent international research in adults and children has reported a decline in burn incidence [29, 35, 36, 38]. While this may be true in the dominant population, studies have often neglected reporting on First Nation children, so trends in these populations are unclear [35, 36, 49, 70].

In Australia, Aboriginal and Torres Strait Islander burn injury hospital admissions are triple those of other Australians [51, 75]. Hospital length of stay (LOS) is proportionally longer for Aboriginal and Torres Strait Islander patients, despite burn severity not differing significantly to other Australian patients [51, 63, 75]. In America and Canada, the mortality rate from unintentional injury is 2-4 times greater for Aboriginal (Native American, Canada - First Nation, Inuit, and Métis peoples) children than other American or Canadian children, with fire related injuries being a common cause [317-321]. Hospitalisation rates from injury are also greater for Native American children [322]. High burn injury rates, longer LOS, and increased morbidity in First Nations children are indicative of health inequities, with people from low SES, minority groups, and regional areas at higher risk [49, 51, 63, 71, 75, 317, 318, 323].

Research published on burns in Australia has generally focussed on Western biomedical models of health, with limited examination of health inequities [52, 63, 70, 74, 79, 82, 324-328]. While First Nation children are overrepresented in burns, to date, no enquiry has used Indigenous research methodologies or methods, which inhibits an authentic understanding of the issues, or development of appropriately contextualised approaches for prevention [7, 83, 84, 145, 329, 330]. In contrast, this study uses Knowledge Interface Methodology (Figure: 12) to analyse data from the Burns Registry of Australia and New Zealand (BRANZ). This paper aims to examine the burns epidemiological profile and risk of bacterial infection using an equity lens, underpinned by decolonisation processes.

4.4 Methods

Design

This research is underpinned by Indigenous methodologies - knowledge interface and decolonisation (Figure 12) [134, 144, 257, 261, 285]. Decolonisation as a research process acts to counteract and redefine unacknowledged processes of power, information and truth generated through the colonisation and imperialism of First Nations communities [288]. The shifting of power dynamics in the research process, by having an Aboriginal research lead the study with support of senior Aboriginal researchers is an example of this [288, 330]. Indigenous knowledge (knowing, being and doing) and Western quantitative knowledge were woven together for this study's knowledge interface, across variable selection, strength-based approach, outcome contextualisation, interpretation and in resetting dominant research norms (Figure 12)[83, 134, 144, 145, 230, 285]. A weaving approach, published by Courtney Ryder [134], was used to ensure the primacy of Indigenous knowledge and experience was privileged. For example, in interpretation naryi kati processes were employed to privilege First Nations voices. Naryi kati repositions quantitative research with an Indigenous lens, in this process other Australian children are not treated or considered as the unacknowledged norm [83 134]. This resetting occurred with an equity focus (as defined by PROGRESS-Plus [n]), to define variables and contextulise outcomes [134]. These processes were limited by the BRANZ, which is constructed from a Western biomedical knowledge system, and which does not conform to Indigenous data sovereignty principles (i.e. data management, interpretation, dissemination)[83, 134, 330]. The BRANZ is a clinical quality and epidemiological data repository, with 17 participating hospitals/burns centres in Australia and New Zealand [51, 52, 331].

Data Source

The BRANZ includes hospital transfers and patients managed by dedicated burns units over three set criteria: 1. Admissions ≥ 24hrs, 2. Admissions ≤ 24hrs requiring surgery and 3. In hospital deaths [51, 52, 331]. Initial admission must occur within 28 days of injury for registry inclusion [51, 52, 331]. The BRANZ Admission data from 1 October 2009 to 31 July 2018 were analysed; participant inclusion criteria required Australian ethnicity, <16 years of age, with an acute burns admission (Appendix A, Figure A.1). Data were extracted under three categories:

[n] PROGRESS-Plus: Place (residence), Race (ethnicity), Occupation, Gender, Religion, Education, Social-capital, Socioeconomic position, Age, Disability, Sexual Orientation, Other Vulnerable Groups[103]

1. Demographics (surrounding PROGRESS-Plus): populated from BRANZ data. A measure of remoteness (Accessibility/Remoteness Index of Australia - ARIA) and SES (SEIFA) were derived from residential postcode [103, 179, 332-334].
2. Injury Characteristics: anatomical location, primary and secondary burns cause as recorded by BRANZ [331].
3. Injury Severity: BRANZ recorded Hospital LOS, %TBSA range, and burns depth variables, and Bacterial Infection derived from International Statistical Classification of Diseases and Related Problems, tenth revision (ICD10-AM) codes (*Staphylococcus sp.* and *Streptococcus sp.* B95)[331, 335].

Analysis

Descriptive statistics (binomial confidence interval) described patient demographics and injury clinical characteristics where, χ^2 tests (categorical) and t-tests (continuous) assessed significance. Univariate and multivariate Poisson regression with robust error variance assessed the risk ratio (95% CI) of bacterial infection (*Staphylococcus sp.* and *Streptococcus sp*.) to covariates (gender, age, ARIA, burns cause, depth and %TBSA). In keeping with knowledge interface methodology, data were stratified by Aboriginal and Torres Strait Islander status. To account for missing data, we used multiple imputation with chained equations and predictive mean matching with 40 imputations (profile – Table 11)[336]. Data were prepared, analysed and plotted with Stata 15.1 (StataCorp), SAS/Stat 14.2 (SAS Institute, Cary, NC, USA) and ggplot2 in [R][337].

Variable	Number missing	%
Length of Stay	**751**	*10.76*
Burn Depth	**539**	*7.72*
Socio-Economic Status	**49**	*0.70*
Regional Area Index	**34**	*0.49*
Primary Burns Cause	**1**	*0.01*
All missing data was imputed.		

Table 11: Profile of Missing Data

Ethics

Ethics approval was acquired from the Human Research Ethics Committee at the University of New South Wales Sydney (HC17712) and the Aboriginal Health & Medical Research Council of New South Wales (1032/14).

4.5 Results

Patient and Injury Characteristics

Of the 6980 children admitted to a BRANZ hospital for an acute burns injury, 723 (10.4%) were recorded as Aboriginal and/or Torres Strait Islander children (Table 12). The gender distribution was similar and there were slight variations for age between groups (Table 12). 'Very low' to 'low' SES was common in all children but the proportion was higher in Aboriginal and Torres Strait Islander children (72.2% vs 43.9%)(Table 12). A greater percentage of Aboriginal and Torres Strait Islander children resided in outer regional to very remote regions compared to other Australian children (61.3% vs 13.9%).

Anatomic locations differed between groups. In Aboriginal and Torres Strait Islander children, hip and lower limb burns were greater compared to trunk burns in other Australian children (Table 13). Scalds were the most common burn cause in all children, with secondary causes differing (Table 14); for example, other Australian children had greater percentages of friction burns by treadmill (1.0% vs 4.9%). Flame burns in Aboriginal and Torres Strait Islander children were higher (19.5% vs 10.6%) across all residential locations (Table 14). The primary cause of burn differed based on residency for Aboriginal and Torres Strait Islander children; the percentage of contact burns increased proportionally with remoteness whilst the inverse was evident in scald burns (Table 14). The proportion of children who had flame burns increased from urban to rural locations (Table 14).

Bacterial infection was greater in Aboriginal and Torres Strait Islander children (Table 15). Percentage TBSA was similar between groups (Table 15); however, a greater proportion of Aboriginal and Torres Strait Islander children (15.6%) had a full thickness burn compared to other Australian children (11.6%; $p<.001$). Aboriginal and Torres Strait Islander children had longer LOS 9.5 days (CI 8.3–10.7) as compared to other Australian children, 4.6 days (CI 4.1–5.0)(Table 15).

	Aboriginal & Torres Strait Islander		Other Australian		Total		
Variable	**Count**	**Proportion (CI)**	**Count**	**Proportion (CI)**	**Count**	**Proportion (CI)**	**P**
Total	723	10.4 (9.7-11.1)	6257	89.6 (88.9-90.3)	6980		
Gender*							0.60
Female	276	38.2 (34.7-41.8)	2443	39.0 (37.8-40.3)	2719	39.0 (37.8-40.1)	
Male	447	61.8 (58.2-65.3)	3812	60.9 (59.7-62.1)	4259	61.0 (59.9-62.2)	
Age							
Mean		4.9 (4.5-5.2)		4.4 (4.3-4.5)		4.4 (4.3-4.5)	0.01
< 1 Year	50	6.9 (5.3-9.0)	744	11.9 (11.1-12.7)	794	11.9 (10.7-12.1)	
1- 4 Years	384	53.1 (49.5-56.7)	3310	52.9 (52.7-54.1)	3694	52.9 (51.8-54.1)	
5 - 9 Years	154	21.3 (18.5-24.4)	1072	17.1 (16.2-18.1)	1226	17.6 (16.7-18.5)	
10 - 15 Years	135	18.7 (16.0-21.7)	1131	18.1 (17.1-19.1)	1266	18.4 (17.3-19.1)	
Regional Area Index							< .001
Metropolitan (RA1)	173	23.9 (21.0-27.2)	3819	61.0 (59.8-62.2)	3992	57.2 (56.0-58.4)	
Inner Regional (RA2)	108	14.9 (12.5-17.7)	1571	25.1 (24.1-26.2)	1678	24.0 (23.1-25.1)	
Outer Regional (RA3)	209	28.9 (25.7-32.3)	677	10.8 (10.1-11.6)	886	12.7 (11.9-13.5)	
Remote (RA4)	121	16.7 (14.2-19.6)	132	2.1 (1.8-2.5)	252	3.6 (3.2-4.1)	
Very Remote (RA5)	113	15.6 (13.2-18.5)	58	0.9 (0.7-1.2)	171	2.5 (2.1-2.8)	
Index of Relative Socio-Economic Advantage and Disadvantage							
Mean		2.0 (1.9-2.1)		2.83 (2.8-2.9)		2.73 (2.7-2.8)	< .001
Very Low: 1-2	370	51.2 (47.5-54.8)	1571	25.1 (24.1-26.2)	1942	27.8 (26.8-28.9)	
Low: 3-4	152	21.0 (18.2-24.1)	1175	18.8 (17.8-19.8)	1327	19.0 (18.1-20.0)	
Medium: 5-6	91	12.6 (10.4-15.2)	1410	22.5 (21.5-23.6)	1501	21.5 (20.6 -22.5)	
High: 7-8	66	9.1 (7.2-11.5)	975	15.6 (14.7-16.5)	1041	14.9 (14.2-15.8)	
Very High: 9-10	44	6.1 (4.6-8.1)	1125	18.0 (17.1-19.0)	1170	16.8 (15.9-17.7)	
* Gender X - Intersex/Indeterminate < 0.00%. Confidence interval – CI. P-Value – **ρ.**							

Table 12: Demographic profile of Australian children admitted to a BRANZ reporting hospital (2009-2018).

	Aboriginal & Torres Strait Islander (n = 723)		Other Australian (n = 6257)		Total (n = 6980)		
Variable	**Count**	**Proportions (CI)**	**Count**	**Proportions (CI)**	**Count**	**Proportions (CI)**	**P**
Primary Burn Cause							**0.002**
Scald	**285**	**39.4 (35.9-43.0)**	**3192**	**51.0 (50.0-52.3)**	**3477**	**49.8 (48.6-51.0)**	
Food/Beverage	115	15.9 (13.4-18.8)	1691	27.0 (25.9-28.1)	1806	25.9 (24.9-26.9)	
Hot Water	132	18.3 (15.6-21.2)	1031	16.5 (15.6-17.4)	1163	16.7 (15.8-17.6)	
Other	38	5.3 (3.9-7.1)	469	7.5 (6.9-8.2)	507	7.3 (6.7-7.9)	
Contact	**229**	**31.7 (28.4-35.2)**	**1587**	**25.4 (24.3-26.5)**	**1816**	**26.0 (25.0-27.1)**	
Coal/Ashes	102	14.1 (11.8-16.8)	366	5.9 (5.3-6.5)	468	6.7 (6.1-7.3)	
Vehicle Exhaust	47	6.5 (4.9-8.5)	305	4.9 (4.4-5.4)	352	5.0 (4.6-5.6)	
Household Surface	18	2.5 (1.6-3.9)	312	5.0 (4.5-5.6)	330	4.7 (4.3-5.3)	
Other	62	8.6 (6.8-10.8)	602	9.6 (8.9-10.4)	664	9.5 (8.9-10.2)	
Flame	**141**	**19.5 (16.8-22.6)**	**662**	**10.6 (9.8-11.4)**	**803**	**11.5 (10.8-12.3)**	

Campfire/Bonfire	53	7.3 (5.7-9.5)	236	3.8 (3.3-4.3)	739	10.6 (9.9-11.3)	
Lighter/Matches	48	6.6 (5.0-8.7)	153	2.5 (2.1-2.9)	289	4.1 (3.7-4.6)	
Other	40	5.5 (4.1-7.5)	272	4.4 (3.9-4.9)	201	2.9 (2.5-3.3)	
Friction	**29**	**4.0 (2.8-5.7)**	**519**	**8.3 (7.6-9.0)**	**312**	**4.5 (4.0-5.0)**	
Treadmill	7	1.0 (0.5-2.0)	308	4.9 (4.4-5.5)	315	4.5 (4.1-5.0)	
Vehicle/Motorbike	20	2.8 (1.8-4.2)	155	2.5 (2.1-3.0)	175	2.5 (2.2-2.9)	
Other	2	0.3 (0.0-0.0)	56	0.9 (0.7-1.2)	58	0.8 (0.6-1.1)	
Other	**39**	**5.4 (4.0-7.3)**	**296**	**4.7 (4.2-5.3)**	**335**	**4.8 (4.3-5.3)**	
Chemical	17	2.4 (1.5-3.7)	101	1.6 (1.3-2.0)	118	1.7 (1.4-2.0)	
Electrical	11	1.5 (0.9-2.7)	49	0.8 (0.6-1.0)	60	0.9 (0.7-1.1)	
Other	5	0.7 (0.3-1.6)	122	2.0 (1.6-2.3)	127	1.8 (1.5-2.2)	
No Cause	6	0.8 (0.4-1.8)	29	0.5 (0.3-0.7)	35	0.5 (0.4-0.7)	
Anatomical Location							
Head & Neck (T20X)	120	16.6 (14.1-19.5)	1100	17.6 (16.7-18.5)	1220	17.5 (16.6-18.4)	
Trunk (T21X)	155	21.4 (18.6-24.6)	1526	24.4 (23.3-25.5)	1681	24.1 (23.1-25.1)	
Shoulder & Upper Limb (T22X)	138	19.1 (16.4-22.1)	1360	21.7 (20.7-22.8)	1498	21.5 (20.5-22.4)	
Wrist & Hand (T23X)	123	17.0 (14.5-19.9)	1306	20.9 (19.9-21.9)	1429	20.5 (19.5-21.4)	
Hip & Lower Limb (T24X)	156	21.6 (18.7-24.7)	1260	20.1 (19.2-21.2)	1416	20.3 (19.4-21.3)	
Ankle & Foot (T25X)	87	12.0 (9.9-14.6)	656	10.5 (9.8-11.3)	743	10.6 (9.9-11.4)	
Confidence interval – CI. P-Value – **ρ.**							

Table 13: Burns Injury Characteristics of Australian children admitted to a BRANZ reporting hospital (2009-2018).

	Scald		Contact		Flame	
ARIA	**Count**	**Proportions (CI)**	**Count**	**Proportions (CI)**	**Count**	**Proportions (CI)**
Aboriginal & Torres Strait Islander Children (n = 723)						
Metropolitan (RA1)	86	50.0 (42.6-57.4)	40	23.3 (17.6-30.1)	27	15.7 (11.0-21.9)
Inner Regional (RA2)	49	45.8 (36.7-55.2)	26	24.3 (17.2-33.2)	20	18.7 (12.4-27.1)
Outer Regional (RA3)	80	38.5 (32.1-45.2)	70	33.7 (27.6-40.3)	45	21.6 (16.6-27.7)
Remote (RA4)	37	30.8 (23.3-39.9)	44	36.7 (28.6-45.9)	26	21.7 (15.2-29.9)
Very Remote (RA5)	32	28.6 (21.0-37.5)	48	42.9 (34.1-52.1)	22	19.6 (13.3-28.0)
Other Australian Children (n = 6257)						
Metropolitan (RA1)	2192	57.7 (56.1-59.2)	708	18.6 (17.4-19.9)	361	9.5 (8.6-10.5)
Inner Regional (RA2)	661	42.3 (39.7-44.8)	536	34.3 (32.0-36.9)	187	12.0 (10.5-13.7)
Outer Regional (RA3)	276	41.0 (37.3-44.7)	244	36.2 (32.7-39.9)	87	12.9 (10.6-15.7)
Remote (RA4)	34	26.0 (19.2-34.1)	60	45.8 (37.5-54.3)	19	14.5 (9.5-21.5)
Very Remote (RA5)	19	32.8 (22.1-45.6)	30	51.7 (39.2-64.1)	4	6.9 (2.7-16.4)
Note: Burn by Friction or Other not included. Confidence interval – CI.						

Table 14: Burns Cause by Residential Location (ARIA) for Australian children admitted to a BRANZ reporting hospital (2009-2018).

	Aboriginal & Torres Strait Islander (n = 723)		Other Australian (n = 6257)		Total (n = 6980)		
Variable	**Count**	**Proportions (CI)**	**Count**	**Proportions (CI)**	**Count**	**Proportions (CI)**	**P**
Bacterial Infection							
Streptococcus	65	9.0 (7.1-11.3)	131	2.1 (1.8-2.5)	196	2.8 (2.5-3.2)	< 0.001
Staphylococcus	104	14.4 (12.0-17.1)	497	7.9 (7.3-8.6)	601	8.6 (8.0-9.3)	< 0.001
Total Body Surface Area %							
Mean		4.4 (3.9-4.8)		4.0 (3.8-4.1)		4.0 (3.9-4.2)	0.07
Unknown	26	3.6 (2.5-5.2)	203	3.3 (2.8-3.7)	228	3.3 (2.9-3.7)	
< 10%	612	84.7 (81.8-87.1)	5450	87.1 (86.3-87.9)	6059	86.8 (86.0-87.6)	
10-19%	61	8.4 (6.6-10.7)	461	7.4 (6.8-8.0)	522	7.5 (6.9-8.1)	
> 19%	24	3.3 (2.2-4.9)	147	2.4 (2.0-2.8)	171	2.5 (2.1-2.8)	
Depth of Injury							**< 0.001**
Superficial Thickness	63	8.7 (6.9-11.0)	695	11.1 (10.4-11.9)	758	10.9 (10.2-11.6)	
Partial Thickness	547	75.7 (72.4-78.6)	4839	77.3 (76.3-78.4)	5386	77.2 (76.2-78.1)	
Full Thickness	113	15.6 (13.2-18.5)	723	11.6 (10.8-12.4)	837	12.0 (11.3-12.8)	
Length of Stay							
Mean		9.5 (8.3-10.7)		4.6 (4.1 – 5.0)		5.1 (4.7-5.5)	**< 0.001**
< 1 day	81	11.2 (9.1-13.7)	2103	33.6 (32.5-34.8)	2168	31.1 (30.0-32.2)	
1 day	86	11.9 (9.7-14.5)	1199	19.2 (18.2-20.2)	1280	18.3 (17.5-19.3)	
2-7 days	276	38.2 (34.7-41.8)	1888	30.2 (29.1-31.3)	2169	31.1 (30.0-32.2)	
8-28 days	242	33.5 (30.1-37.0)	918	14.7 (13.8-15.6)	1173	16.8 (16.0-17.7)	
> 28 days	39	5.4 (4.0-7.3)	148	2.4 (2.0-2.8)	189	2.7 (2.4-3.1)	
Confidence interval – CI. P-Value – **ρ.**							

Table 15: Burn Cause by Residential Location (ARIA) for Australian children admitted to a BRANZ reporting hospital (2009-2018).

Characteristics associated with infection after burns

In Aboriginal and Torres Strait Islander children the risk ratio of *Streptococcus sp.* infection was 4.3 times greater (9.0, [CI 7.1-11.3]) than other Australian children (2.1 [CI 1.8-2.5]). The risk ratio of *Staphylococcus sp.* infection was even greater in Aboriginal and Torres Strait Islander children (14.4, [CI 12.0–17.2]), compared to other Australian children (8.0, [CI 7.3-8.6]). In univariate analyses stratified by Aboriginal and Torres Strait Islander status, several factors were significantly associated with *Staphylococcus sp.* infection in Aboriginal and Torres Strait Islander children, including flame burns and TBSA >10% (Table 16). The same was evident for *Streptococcus sp.* infection, but for TBSA > 19% and rural residency. In other Australian children, flame and %TBSA were also significant risks for infection, with *Streptococcus sp.* infection risk in burns above 19% double that of Aboriginal and Torres Strait Islander children. Additional risks for other Australian children included age (1 to 4 years), partial or full thickness

burns for S*taphylococcus sp.* infection, and partial thickness burns and burns greater than 10% TBSA for *Streptococcus sp.* infection.

In the multivariable model, flame burns, burns above 19% TBSA and rural residency remained risks for *Streptococcus sp.* infection, with female gender emerging as a risk in Aboriginal and Torres Strait Islander children (Table 17, Figure 13). Burns above 10% TBSA remained as a risk for *Staphylococcus sp.* infection in Aboriginal and Torres Strait Islander children. Full and partial thickness burns, age 1 to 4 years remained as a risk for *Staphylococcus sp.* infection, burns above 10% remained as a risk of infection for either species in other Australian children (Table 17, Figure 13).

		Staphylococcus sp.		**Streptococcus sp.**	
Variable	**Level**	**Aboriginal and Torres Strait Islander OR**	**Other Australian OR**	**Aboriginal and Torres Strait Islander OR**	**Other Australian OR**
Gender	Male	Reference	Reference	Reference	Reference
	Female	1.02 (0.67 - 1.56)	1.01 (0.84 - 1.22)	1.54 (0.92 - 2.56)	1.17 (0.83 - 1.66)
Age Category	Less than 1 year	Reference	Reference	Reference	Reference
	1 to 4 years	0.86 (0.37 - 1.98)	1.38 (1.01 - 1.89)	0.59 (0.22 – 1.56)	0.89 (0.53 - 1.49)
	5 to 9 years	1.03 (0.41 - 2.57)	1.07 (0.74 - 1.55)	1.12 (0.41 - 3.10)	0.72 (0.38 - 1.37)
	10 to 15 years	1.31 (0.54 - 3.16)	1.18 (0.82 - 1.71)	1.22 (0.44 - 3.41)	0.76 (0.40 - 1.44)
Depth	Superficial Thickness	Reference	Reference	Reference	Reference
	Partial Thickness	1.93 (0.72 - 5.16)	4.22 (2.51 - 7.10)	2.02 (0.54 - 7.52)	2.37 (1.07 - 5.24)
	Full Thickness	1.77 (0.59 - 5.29)	2.41 (1.31 - 4.41)	2.10 (0.50 - 8.83)	1.92 (0.74 - 4.95)
Burn Category	Scald	Reference	Reference	Reference	Reference
	Contact	1.20 (0.72 - 2.01)	0.76 (0.60 - 0.96)	0.85 (0.43 - 1.66)	0.51 (0.31 - 0.85)
	Flame	1.99 (1.17 - 3.41)	1.33 (1.01 - 1.74)	2.20 (1.18 - 4.12)	1.65 (1.04 - 2.61)
	Other	1.02 (0.46 - 2.29)	0.73 (0.53 - 0.99)	1.22 (0.48 - 3.06)	0.64 (0.35 - 1.17)
ARIA	Metropolitan (RA1)	Reference	Reference	Reference	Reference
	Inner Regional (RA2)	0.57 (0.27 - 1.22)	0.81 (0.64 - 1.01)	0.22 (0.06 - 0.88)	0.73 (0.48 - 1.13)
	Outer Regional (RA3)	0.45 (0.24 - 0.87)	0.87 (0.64 - 1.18)	0.45 (0.20 - 1.03)	0.77 (0.43 - 1.40)
	Remote (RA4)	1.48 (0.82 - 2.69)	0.93 (0.49 - 1.76)	1.71 (0.84 - 3.49)	0.79 (0.22 - 2.83)
	Very Remote (RA5)	1.54 (0.84 - 2.82)	0.68 (0.23 - 2.05)	2.10 (1.04 - 4.23)	0.36 (0.02 - 5.93)
%TBSA Range	Less than 10%	Reference	Reference	Reference	Reference
	10% to 19%	2.09 (1.10 - 3.94)	3.32 (2.57 - 4.29)	1.58 (0.69 - 3.58)	4.20 (2.70 - 6.54)
	Greater than 19%	7.04 (3.06 - 16.2)	6.55 (4.55 - 9.42)	7.22 (3.01 - 17.3)	12.0 (7.25 - 19.7)

Table 16: Stratified univariate analysis for Staphylococcus sp. and Streptococcus sp. Infection (relative to no infection)

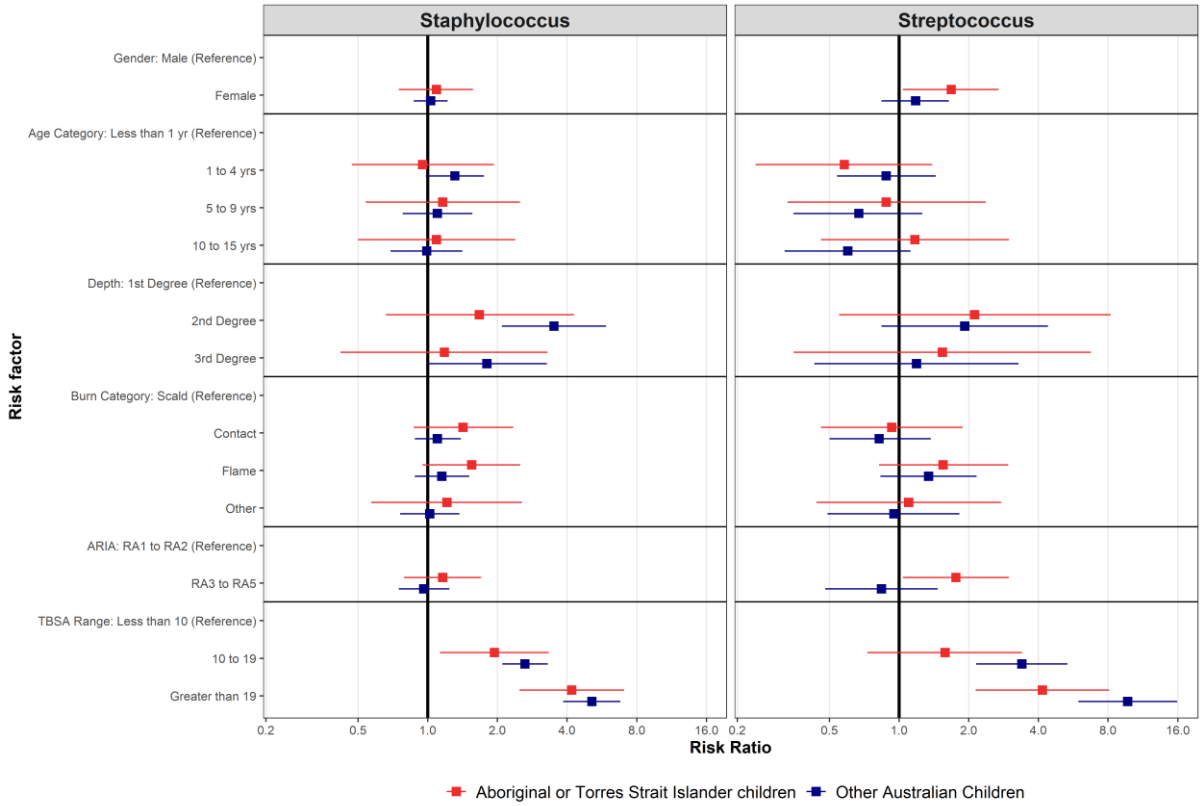


Figure 13: Risk ratio of staphylococcus sp. and streptococcus sp. infection for Aboriginal and Torres Strait Islander children and other Australian children.

	Staphylococcus sp.		Streptococcus sp.	
Variable	**Aboriginal & Torres Strait Islander RR**	**Other Australian RR**	**Aboriginal & Torres Strait Islander RR**	**Other Australian RR**
Gender (Reference: Male)				
Female	1.1 (0.8 - 1.6)	1.0 (0.9 - 1.2)	**1.7 (1.0 - 2.7)**	1.2 (0.8 - 1.6)
Age (Reference: Less than 1 year)				
1 to 4 years	1.0 (0.5 - 1.9)	**1.3 (1.0 - 1.8)**	0.6 (0.2 - 1.4)	0.9 (0.5 - 1.4)
5 to 9 years	1.2 (0.5 - 2.5)	1.1 (0.8 - 1.6)	0.9 (0.3 - 2.4)	0.7 (0.4 - 1.3)
10 to 15 years	1.1 (0.5 - 2.4)	1.0 (0.7 - 1.4)	1.2 (0.5 – 3.0)	0.6 (0.3 - 1.1)
Depth of Injury (Reference: Superficial Depth)				
Partial Thickness	1.7 (0.7 - 4.3)	**3.5 (2.09 - 5.90)**	2.1 (0.6 - 8.2)	1.9 (0.8 - 4.4)
Full Thickness	1.2 (0.4 - 3.3)	**1.8 (1.0 - 3.3)**	1.5 (0.4 - 6.7)	1.2 (0.4 - 3.3)
Primary Burn Cause (Reference: Scald)				
Contact	1.4 (0.9 - 2.3)	1.1 (0.9 - 1.4)	0.9 (0.5 - 1.9)	0.8 (0.5 - 1.4)
Flame	**1.6 (1.0 - 2.5)**	1.2 (0.9 - 1.5)	1.6 (0.8 – 3.0)	1.3 (0.8 - 2.2)
Other*	1.2 (0.6 - 2.6)	1.0 (0.8 - 1.4)	1.1 (0.5 - 2.8)	1.0 (0.5 - 1.8)
Regional Area Index (Reference: Metropolitan to Inner Regional RA1-RA2)				
Outer Regional to Very Remote (RA3-RA5)	1.2 (0.8 - 1.7)	1.0 (0.8 - 1.2)	**1.8 (1.0 – 3.0)**	0.8 (0.5 - 1.5)
% Total Body Surface Area (Reference: Less than 10%)				
10% to 19%	**1.9 (1.1 - 3.3)**	**2.6 (2.1 - 3.3)**	1.6 (0.7 - 3.4)	**3.4 (2.2 - 5.3)**
Greater than 19%	**4.2 (2.5 - 7.1)**	**5.1 (3.9 - 6.8)**	**4.2 (2.1 - 8.1)**	**9.7 (6.0 - 15.9)**
* Other – chemical, electrical, friction and other burns. Multivariate risk ratio – RR.				

Table 17: Multivariate risk ratio (RR) is infection by bacterial species (relative to no infection) in Australian children admitted to a BRANZ reporting hospital (2009-2018).

4.6 Discussion

Health inequities for First Nations children hospitalised for a burns injury clearly remains an important social and healthcare issue. Aboriginal and Torres Strait Islander children are over-represented for burns injury admissions- 10.8% of this registry, while representing approximately 5.3% of the Australian population from 0 to 15 years [338]. In Australia, 44% of Aboriginal and Torres Strait Islander people reside in outer regional to remote areas, as opposed to 10% of other Australian children [339]. Over 60% of Aboriginal and Torres Strait Islander children in this study resided in these regions, compared to 14% of other Australian children, highlighting the importance of rural residency as a health inequity for these children. While very low SES was common in any Australian child hospitalised with a burns injury, this proportion was more pronounced in Aboriginal and Torres Strait Islander children where over 70% of Aboriginal and Torres Strait Islander children came from low to very low SES backgrounds. Greater proportions of low SES have been reported in Native American children and Māori patients admitted for burn injury [340, 341]. These results are indicative of impacts from economic marginalisation and social exclusion that First Nations communities experience from continued colonisation in the form of colonialism (political exclusion, racism, transgenerational trauma) [9, 144, 342]. Australia, like most colonised countries, exists in a state of neo-colonialism where colonisation continues to impact on Aboriginal and Torres Strait Islander communities through structural oppressions; be that land dispossession, racism, transgenerational trauma, health inequities or political control and assimilation (ie cashless welfare cards)[9, 144, 342].

We found LOS for Aboriginal and Torres Strait Islander children to be double that of other Australian children. In this study, our mean of 9.4 days was greater than previous reporting of 6.1 days [63], perhaps reflecting the use of national data over a nine year period. The longer LOS for Aboriginal and Torres Strait Islander children could be explained by the cause of burn, severity and the patient's place of residence. Similarly longer hospital LOS has been reported in Native American communities [343]. Scalds were the most common cause of burns in Australian children [51, 52, 63, 324], but they decreased as the cause of a burn with increasing remoteness, which is consistent with prior reporting [71, 344]. In contrast, the proportion of cases with contact burns increased with remoteness in both child groups, unlike some past reports [344]. These differences may be due to specific amenities being more common rurally, such as the 'pot belly' stoves, open fire places, convection ovens or cooktops, and outdoor kitchen facilities [71-73]. Flame burn incidence was greater in Aboriginal and Torres Strait Islander children across all areas of remoteness, which is consistent with previous Australian research and comparable to

both Canadian Aboriginal children and Native American communities [63, 284, 341, 343, 345]. Greater exposure to outdoor-related activities, such as camping, bonfires and motorbikes are more common in rural areas and may contribute to these contact and scald results [68, 72, 73].

In Aboriginal and Torres Strait Islander children, flame burns and high %TBSA (>19%) was a risk for infection of both bacteria species. After adjusting for patient and injury characteristics, %TBSA remained as a risk factor. Flame burns remained as a risk for *Staphylococcus sp.* infection and rural residency remained for *Streptococcus sp.* infection. Delayed access to specialised burns centres located in major Australian cities, due to distance and transport availability, may contribute to this finding. Infection with *Streptococcus sp.* is of particular concern in burns as unless this infection is cleared before any skin grafting procedure the loss of the graft is more likely to occur, increasing LOS and the potential for additional operative interventions. The risk of infection with this species was four times greater in Aboriginal and Torres Strait Islander children than other Australian children. Reoccurring *Streptococcus sp.* skin infections can cause acute post-streptococcal glomerulonephritis (APSGN) in children, and in Aboriginal and Torres Strait Islander communities this is an identified risk factor for renal disease later in life [346-349]. Incidence of APSGN in Aboriginal children in the Northern Territory is reported at 124 cases per 100, 000 person-years as compared to 17 cases per 100, 000 person-years for other-Australian children, however recent research has suggested this could be as high as 228 cases per 100,00 person years for Aboriginal children in Central Australia [347, 350]. This health inequity may be minimised in these cases through careful education, ongoing monitoring, and early treatment of Aboriginal and Torres Strait Islander burn injury survivors and their family, to help prevent further manifestation of *Streptococcus sp.* or significant comorbidities later in life. This health inequity may be minimised in these cases through careful education, ongoing monitoring and the early treatment of Aboriginal and Torres Strait Islander burns injury survivors and their family to help prevent further manifestation of *Streptococcus sp.* or significant comorbidities later in life.

The burns profile for Aboriginal and Torres Strait Islander children is different to other Australian children. In this profile, persistent health inequities are present, through higher proportions of remote residency, lower SES (a manifestation of ongoing colonisation), longer LOS and increased burns severity (full thickness depth, bacterial infection). Clinical teams need to carefully consider the broader impact of the burns injury on Aboriginal and Torres Strait Islander children and their families. Limited access to local tertiary health and specialised

outpatient services in Australia results in rural and remote children having longer hospital LOS [68, 351]. The need to access specialised health services becomes an extra burden on families (ie financial, community responsibilities or sibling impacts)[63]. Furthermore, all burns survivors can expect to face months, even years of ongoing treatment, including further surgery and ongoing therapies. Prevention programs, clinical guidelines, injury rehabilitation programs, education programs and government policy looking to target inequities in burns injuries must first target overall health inequities, with a strong focus on the multiple determinants of First Nations' health and concepts of health and well-being [68, 103, 352, 353]. Central to this is a focus on cultural safety, so that initiatives or programs can be designed and tailored to meet the needs of First Nations children and their families [352].

Strengths and Limitations

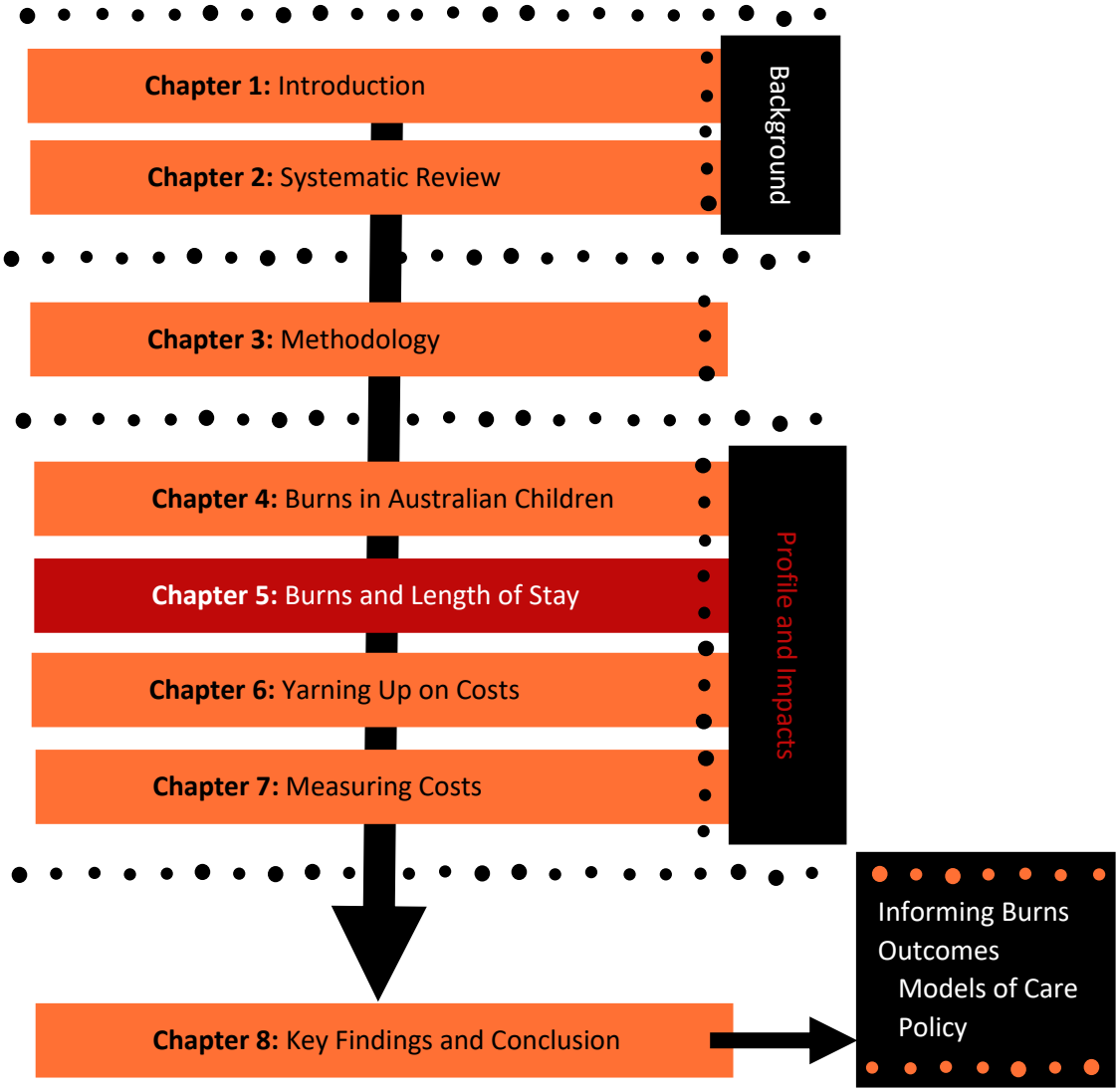
At the time of this study the BRANZ covered 14 hospitals in Australia. This included all Paediatric Burn Centres in Australia, however children with minor burns may have been treated elsewhere. Not all BRANZ hospitals have been reporting for the same amount of time. Postcode were used to create SES and may not be a true indication for individual patients. Our results are likely to demonstrate an underrepresentation of Aboriginal and Torres Strait Islander children due to underreporting in routinely collected data [63, 354]. Strengths of this paper include a principled approach to account for missing data, engagement with a health equity enquiry and application of knowledge interface and decolonisation methodologies led by the Aboriginal first author.

4.7 Conclusion

Noticeable health inequities exist in the epidemiological profile of acute burns in Australian children. Aboriginal and Torres Strait Islander children have longer hospital LOS for their injuries which places an additional burden on families, especially those residing in rural locations and from lower SES backgrounds. Higher risks of bacterial infection are present in Aboriginal and Torres Strait Islander children, adding further challenges and potential for progression of other diseases later in life. For meaningful change, programs, policies and clinical guidelines targeting burns prevention and treatment must engage with health inequities present in the burns profile of Australian children, especially for Aboriginal and Torres Strait Islander communities.

CHAPTER 5

Factors Contributing to Longer Length of Stay in Aboriginal and Torres Strait Islander Children Hospitalised for Burns Injury



5.1 Preamble

Aboriginal and Torres Strait Islander children have a greater burns incidence and hospital LOS for their burns, compared to other Australian children [63, 69, 75, 77, 78]. Chapter 4 highlighted the magnitude of health inequities affecting Aboriginal and Torres Strait Islander children hospitalised with an acute burns injury. However, this chapter did not identify the relationship between health inequities and hospital LOS. This chapter focusses on examining prognostic factors which increase hospital LOS for Aboriginal and Torres Strait Islander children and includes exploring the health inequities. The outcomes from this study informed recommendations in Chapter 7.

This chapter is has been published in:

Ryder, C., Mackean, T., Hunter, K., Towers, K., Rogers, K., Holland, A.J.A., and Ivers, R., Factors Contributing to Longer Length of Stay in Aboriginal and Torres Strait Islander Children Hospitalised for Burn Injury. Journal of Injury Epidemiology. 2020. 7(52).

Corresponding Author: Courtney Ryder

Published: 5 October 2020

5.1.1 Summary: Weaving the Interface

> *"A change in the paradigm of Indigenous data is required with an Indigenous data voice a prerequisite to reshaping practices to allow Indigenous data to be a resource for Aboriginal and Torres Strait Islander peoples' development agendas".*
>
> Maggie Walter[84(p.263)]

The challenges and limitations of working with a national registry data, in this case the BRANZ, have been previously outlined in Chapters 3 and 4. In addition, the weaving methodology for 'research at the interface' used in this thesis and each study, is outlined in Chapter 3. Similar to Chapter 4, this study drew upon the knowledge interface, decolonisation, nayri kati and Indigenist research methodologies for the weaving approach in the study, using the process outlined in Chapter 3 and illustrated in Figure 14.

There are five main sections (Figure 14) which make up the shape and structure of this study's woven interface. The strands and intersectional points of the weave which make up each of these sections will be described to provide readers with an appreciation of the Indigenous and Western knowledge systems which are part of this woven interface. In addition, the four main

principles at the interface for this study will also be outlined: Mutual Respect, Shared Benefits, Human Dignity and Discovery.

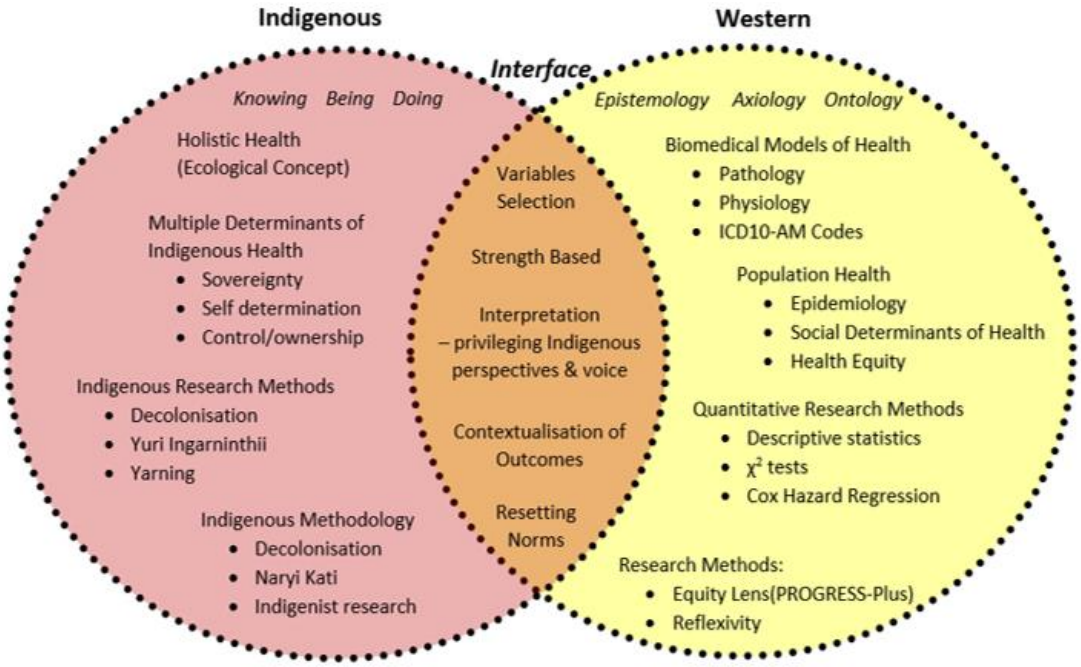


Figure 14: Visual representation of research at this knowledge interface Chapter 6.

Variable Selection

The majority of the BRANZ variables focus on Western biomedical models and constructs of health. The BRANZ variable of Ethnicity provides patients with autonomy as a variable based on cultural affiliation, rather than "race, ancestry, nationality or citizenship" [331]. Western knowledge for model for health (burns pathology, ICD10AM codes), population health (social determinants of health, health inequities), Western research methods (Equity Lens - PROGRESS-Plus) (Chapter 2 – for description) and Indigenous Knowledge of methodology (naryi kati, decolonisation), multiple determinants of Indigenous health and Indigenous research methods (decolonisation) were used to select variables. The objectives was to ensure that variable selection focussed on contextualising measures of health equity but still reflecting the multiple determinants of Indigenous health. This included deciding which variables would be part of the analyses for descriptive statistics and the Cox Regression model for hospital LOS.

Strength Based

A strength based research approach was critical to this study to ensure that negative study designs and negative data narratives for Aboriginal and Torres Strait Islander communities

were avoided. This required using processes of Indigenous research methodology, nayri kari, to not start from an Indigenous deficit model [83, 84]. It was also significantly important for Indigenous knowledge (holistic health, multiple determinants of Indigenous health) to be drawn on from the knowledge and lived experience of Ryder, her Aboriginal supervisor and other Aboriginal chief investigators of the Coolamon study, for the overall conceptualisation of the study. As an example, burns literature has identified hospital LOS is greater for Aboriginal and Torres Strait Islander children, but has not explained why. Whereas this study employs Indigenous Knowledge or methodologies, to understand prognostic factors which increase LOS for Aboriginal and Torres Strait Islander children.

Using a strength based approach did not mean that negative study outcomes were not reported: it meant that they were contextualised using Indigenous and Western knowledge on health inequities. Focussing on a strength based process was essential for the overall construction of this chapter, but also in ensuring a strength based approach was taken in the narrative of this chapter. Indigenous Knowledge on decolonisation, and the multiple determinants of Indigenous health, were used to structure the wording of the paper to reflect Indigenous perspectives and voice, for example:

- longest surviving civilisation in the world instead of oldest continuing culture in the world
- Implicit bias, from whiteness, racialisation of Aboriginal and/or Torres Strait Islander identity and presumptive beliefs on remoteness instead of not highlighting this limitation in the Western clinical environment
- colonial constraints and whiteness are present in the BRANZ instead of not acknowledging this limitation.

Interpretation – Privileging Indigenous Perspectives and Voice

Western knowledge of biomedical models of health, population health, quantitative research methods and the equity lens were a significant part of this interface. To ensure that the woven interface was not focussed on privileging this knowledge, and that it was contextualised to ensure Indigenous perspectives and voices were privileged, Indigenous Knowledge for holistic health, multiple determinants of Indigenous health, decolonising processes and Indigenous research methodologies (nayri kati and Indigenist research) were engaged with at the interface.

Firstly, an Aboriginal student undertook this study whom brings her own lived experience and appreciation to this study. This is an important process in decolonisation, nayri kati and Indigenist research, and in reshaping quantitative research agendas towards Indigenous data sovereignty [83, 144, 252, 311, 330]. Indigenist research processes of "Political Integrity" were enacted through engaging closely with Aboriginal chief investigators, Ryder's Aboriginal supervisor as well as Ryder's personal lived experience, to contextualise analyses and ensure Indigenous perspectives were privileged [252]. Wherever possible, descriptive statistics surrounding Aboriginal and Torres Strait Islander children came from national data which conforms to principles of Indigenous data sovereignty [9, 83, 252]. These actions were part of the critical processes of 'privileging Indigenous voices' in Indigenist research and prioritising Indigenous Knowledge in nayri kati [83, 252]. As such, these actions engaged with processes which acted to decolonise the data narrative in this area.

Contextualisation of Outcomes

Western Knowledge surrounding quantitative research methods[o] (descriptive, Cox Regression), population health (social determinants of health, health inequities), Western research methods (equity lens, reflexivity) and Indigenous Knowledge for methodology (naryi kati, decolonisation, Indigenist research) with Indigenous research processes (decolonisation, yuri Ingarninthii and yarning) were used to contextualise analysis outcomes.

Specifically, Ryder undertook the process of Yarning surrounding outcomes with her supervisor and clinical staff (surgeons, registered AHP) who are chief investigators on the Coolamon Study. These Yarning sessions were conducted one on one and focussed on Yarning around the outcomes from analyses, but with Western knowledge from population health and Indigenous Knowledge from multiple determinants and holistic health. Reflexivity with processes of decolonisation were then engaged with, focussing on the outcomes from these Yarning sessions, to activate yuri Ingarninthii processes. These processes acted to strengthen the data narrative so that the lived experience and stories behind the outcomes could be connected with, and articulated, in the manuscript discussion.

Resetting Norms

[o] In this analysis it should be understood and acknowledged that Western knowledge for biomedical models of health (burn pathology, ICD10-AM codes) are present. This knowledge is not unacknowledged normative knowledge.

It was important that the normative colonial framework, which all too often shapes Indigenous health outcomes in a deficit model, was reset. To challenge this often unacknowledged colonial hegemony, Indigenous Knowledge surrounding the multiple determinants of Indigenous health, and Indigenous research methodologies of nayri kati, decolonisation and Indigenist research, were used with Western quantitative research outcomes, and Western understandings of health inequities.

Resetting norms included ensuring that 'other Australian children were not the unacknowledged norm' or that we started from an 'Indigenous deficit model', using principles from Indigenist research and nayri kati [83, 84, 174, 252]. For this, analyses and outcomes were stratified for Aboriginal and Torres Strait Islander children and other Australian children; results were focussed on Aboriginal and Torres Strait Islander children and if comparison between groups occurred it was undertaken encompassing health inequities and the multiple determinants of Indigenous health. This included acknowledging the Western colonial hegemony present in the BRANZ. For example, the BRANZ uses ICD10-AM coding, which does not code for treatment with Aboriginal Health Workers, AHP or ALO. Despite this, the BRANZ does not have any additional measures which record this information. In addition, the limitations of drawing on the data narrative for burns injury prognostic factors needed to be acknowledged – an important nayri kati process in ensuring that Western scientific constructs are not the unacknowledged norm [83]. The majority of these studies are founded and analysed from Western knowledge and significant care must be taken when referencing this material; it must be accounted for, and contextualised, when being used in Aboriginal and Torres Strait Islander health.

ARE WE AT THE INTERFACE?

There are four important principles that determine if research is at the interface.

Mutual Respect

For this principle, research must recognise the "validity of both knowledge systems" [1]. This recognition in understanding the strengths and weaknesses of each system, but allowing each system its own shared space so that when each knowledge system collaborates, it is for the best outcomes of the interface [1]. The five main sections of the interface for this study are outlined above, and mutual respect is evident through the prioritisation of Indigenous perspectives and voice, to engage with the use of quantitative research measures. Each section has been woven using a balance of Indigenous and Western Knowledge, to

complement the strength of each system and act to enhance the analysis and outcomes of the research question.

Shared Benefits

This principle is focussed on ensuring that not only one knowledge system benefits from the research [1]. The benefits for Western knowledge are evident – the use of scientific conventions and BRANZ data contribution to academic discourse. As outlined above, Indigenous perspectives and voices were privileged, having been privileged since the conception of this study. This was critical to the principle of shared benefits and included such factors as: the research was conducted by an Aboriginal PhD student; it was supported by other Aboriginal experts and drew upon national Australian statistics which conform to Indigenous data sovereignty principles, where possible referencing First Nations scholars. Resetting Norms was also an important part of ensuring that shared benefits occurred, so that a negative deficit discourse founded in Western colonial constructs did not ensue [84, 252].

Human Dignity

> *"Personal integrity, cultural identity and associated bodies of knowledge should not be devalued or lightly dismissed because they do not accord with the belief systems of some researchers".*
>
> Mason Durie [1(p. 11)]

In each of the five sections which make up this woven research interface, human dignity is evident. This is apparent through the use of Indigenous Knowledge to select variables for analysis, using a strength based narrative which does not follow a starting principle of 'Indigenous deficit', drawing on Indigenous voice and perspectives, Yarning up with experts in burns injury, the use of yuri Ingarninthii processes to highlight the narrative behind the data and through to the resetting of norms [83]. While Western knowledge and research processes were used, and provided the space they needed for their use, it was also important to identify the limitations for this research, such as using the BRANZ which does not conform to principles of Indigenous data sovereignty.

Discovery

"Discovery of new knowledge is at the heart of all research".

Mason Durie [1(p.11)]

The discovery and new knowledge which is occurring at this research interface is the way in which the research outcomes are contextualised. Resetting norms and variable selection have been critical in providing space for Indigenous perspectives and voice, critical to discovery, new ways of analysing outcomes, and providing a different data narrative, one which works towards the principles of Indigenous data sovereignty. This research interface provides an approach for the future, where Indigenous Knowledge is central and paramount to the outcomes from research. It is this discovery, and new knowledge, that allows a different perspective, a fresh approach for clinical and policy stakeholders, peak Aboriginal and Torres Strait Islander health bodies and national health promotion initiatives and will be applicable to other First Nations communities internationally.

> *"In 1967 we were counted, in 2017 we seek to be heard. We leave base camp and start our trek across this vast country. We invite you to walk with us in a movement of the Australian people for a better future".*
>
> Uluru Statement from the Heart [133]

5.2 Abstract

Background: Aboriginal and Torres Strait Islander children have higher incidence, severity and hospital LOS for their acute burns injuries than other Australian children. We examined factors contributing to longer LOS for Aboriginal and Torres Strait Islander children with an acute burns injuries.

Methods: The BRANZ admissions of children <16 years of age between October 2009 and July 2018 were analysed. Descriptive statistics explored patient and injury characteristics and Cox Regression models estimated characteristics associated with longer LOS. Knowledge Interface methodology and Indigenous research methods were used throughout.

Results: A total of 723 children were identified as Aboriginal and Torres Strait Islander and 6257 as other Australian. The median hospital length of stay for Aboriginal and Torres Strait Islander children (5 days [CI 5-6] was 4 days longer than other Australian children (1 day [CI 1-2]). Remoteness, flame burns, high %TBSA and full thickness burns were factors associated with longer LOS for Aboriginal and Torres Strait Islander children. Similar prognostic factors were identified for other Australian children, along with Streptococcus sp. and Staphylococcus sp. infections.

Conclusion: Remoteness, flame burns, %TBSA and full thickness burns are prognostic factors contributing to extended hospital LOS for all Australian children. These factors are more prevalent in Aboriginal and Torres Strait Islander children, impacting LOS. Treatment programs, clinical guidelines and burns policies should engage with the unique circumstances of Aboriginal and Torres Strait Islander children to mitigate inequities in health.

5.3 Introduction

Aboriginal and Torres Strait Islander people, one of the longest surviving civilisations in the world, make up 3% of the Australian population, over 700,000 people [8, 355]. Similar to other First Nations peoples globally impacted by colonisation, they face significant and ongoing health disparities, with a disease burden 2.3 times greater and a life expectancy 10 years less than other Australians [8, 355]. This burden is reflected in a young age profile, where 34% of Aboriginal and Torres Strait Islander people are under 15 years of age, compared to 18% of other Australians [8]. Further comparison to other Australian children reveals significant disadvantage across a range of social exclusion indicators, such as lower numeracy and literacy levels, financial hardship and anxiety induced by racism [7, 9-12]. These inequities in social exclusion indicators are indicative of transgenerational trauma and ongoing marginalisation. Despite this adversity, Aboriginal and Torres Strait Islander children remain strong and

resilient, demonstrating higher levels of social consciousness (compassion, empathy and caring) than other Australian children [7, 10].

Injury is a significant cause of morbidity in Aboriginal and Torres Strait Islander children [8, 78]. Specifically, burns injury rates are 2-3 times greater for Aboriginal and Torres Strait Islander children as compared to other Australian children [69, 75]. They also represent one of the most common injuries requiring medical attention for Aboriginal and Torres Strait Islander children <6 years of age [77, 78]. As an injury, burns are complex, resource intensive and costly, creating significant occupation and social limitations [40, 41, 356, 357]. Depending on severity, children and their families can have extensive hospital lengths of stay (LOS) for the initial treatment, as well as ongoing rehospitalisation for treatment and scar management. The average hospital LOS in Aboriginal and Torres Strait Islander children hospitalised for asthma, chest or skin infections is 2-5 nights; for burns injuries it is 6 nights [63, 77, 78]. Long admissions can cause significant trauma, instigating episodes of post-traumatic stress in parents, which also impacts adversely on a child's recovery and health outcomes [27, 358]. These are factors which can be exacerbated in Aboriginal and Torres Strait Islander families, who already face high levels of trauma, and who typically place less trust in the hospital system than their general practitioner [313].

Internationally, there is a sound body of knowledge surrounding prognostic factors for hospital LOS in burns injuries [47, 64, 65, 357-363]. In adults, %TBSA, full thickness burns, SES, age, inhalation injury, comorbidities, surgical interventions and injury complications have been shown to be associated with a longer LOS [357-363]. In children with a burns injury, large %TBSA (>16%), burns cause (scald or flame compared to other types) and full and partial thickness burns increase LOS, whereas younger age and early skin grafting decrease LOS [47, 64, 65]. There has been comparatively limited research focussing on understanding the prognostic factors contributing to longer LOS for burns injury in First Nations children. Most Australian burns research has focussed on children or adults, without exploration of outcomes for Aboriginal and Torres Strait Islander people. To date, this burns injury enquiry has lacked contextualisation and appropriate analyses for Aboriginal and Torres Strait Islander communities. These processes inhibit the development of appropriate care pathways and prioritisation of Indigenous approaches to health and well-being for burns injuries. Therefore, our objectives were to engage with Indigenous research methodologies to identify prognostic factors of LOS in acute burns injuries for Aboriginal and Torres Strait Islander children and examine the contributing health inequities.

5.4 Methods

The BRANZ captures data from 17 specialist burns centres in Australia and New Zealand, with 11 of these contributing paediatric data [51, 52, 331]. With sole purpose to monitor burns incidence and causality, the BRANZ is described as a clinical epidemiological repository [51]. The registry includes patients admitted within 28 days of their injury, burns transfers and cases managed by dedicated burns units [51, 52, 331]. The BRANZ was established before the full conceptualisation and appreciation of Indigenous data sovereignty, and as such, does not have Aboriginal and Torres Strait Islander governance surrounding status identification, data collection, data analyses or outcome translation [84, 330]. We therefore employed decolonising and knowledge interface methodologies in this study (Figure 14)[83, 144, 230, 285, 330]. Indigenous knowledges were important for the overall study conceptualisation (variable selection, statistical analyses, results interpretation) and the first author drew on their own lived experience as an Aboriginal woman, and engaged in yarning and yuri ingarninthii[p] processes with other experts (Aboriginal Public Health Physician, Associate Professor Tamara Mackean) and a Registered AHP specialising in burns (Kurt Towers) to strengthen this process (Figure 14)[2, 292].

Data Source

The BRANZ data included in this study were any records with admission between 1st October 2009 and 31st July 2018 for Australian children (<16 years) with an acute burns admission to an Australian hospital. Data was extracted under the following categories (Variable Details – Appendix B, Table B.1):

4. Demographics): Gender, Age, Accessibility/Remoteness Index of Australia (ARIA) and SES.
5. Injury Severity: Burn Cause, %TBSA, Burn Depth and Bacterial infection.
6. Injury Treatment: Burn Dressing, Burn Debridement, Split Skin Graft, Physio/Occupational Therapy, Psychology/Social Work and Other Allied Health (Appendix B, Table B.1).

Statistical analysis

Descriptive statistics were used to describe patient demographics and injury and treatment characteristics. Continuous variables were summarised with mean, standard deviation and median. Categorical variables were summarised as the proportion of the patients for each level of the variable. Missing data on patient characteristics were imputed in a multiple imputation procedure using chained equations with predictive mean matching over 40 imputations [336].

[p] Yarning is a conversational technique for data collection and discussion. Yuri ingarninthii, a Kaurna term, is a form of deep listening. Both are used in Indigenous research.

Crude hospital LOS was represented visually through inverse survival hazard estimates in both child groups (with 95% CI) and the median time to discharge (with 95% CI) was estimated.

A four staged Cox Regression model, stratified by Aboriginal and Torres Strait Islander status, was developed to examine factors which increased hospital LOS for both Aboriginal and Torres Strait Islander children and for other Australian children. Hazard ratio outputs from the model, where survival time was hospital LOS, were described as the discharge ratio[q] (95% CI), in the model. Higher discharge ratios reflect longer LOS. Each stage introduced new variables to the model:

Stage 1 (Table 18): Patient Demographics: Gender, Age Range, ARIA and SES

Stage 2 (Table 19): Injury Cause

Stage 3 (Table 20): Injury Severity: %TBSA, Depth and Wound Bacterial Infection

Stage 4 (Table 21): Injury Treatment: Burn Dressing, Burn Debridement, Split Skin Graft and Allied Health Intervention.

The proportional hazards assumption for each variable was checked on the first imputation of the data set, using visualisations of the cumulative sum of martingale residuals over follow-up. Data were prepared, analysed and plotted with Stata 15.1 (StataCorp, Texas, TX USA) and SAS/Stat 14.2 (SAS Institute, Cary, NC, USA).

Ethics approval

The Human Research Ethics Committee at the University of New South Wales Sydney (HC17712) and Aboriginal Health & Medical Research Council of New South Wales (1032/14) approved ethics for this study.

5.5 Results

Patient Demographics and Injury Severity

From 01 October 2009 to 31 July 2018, 6980 children were admitted to a BRANZ reporting hospital for an acute burns injury. Of this cohort 10.4% (CI 9.7-11.1) were recorded as an Aboriginal and/or Torres Strait Islander child (Table 18). The median LOS in hospital for Aboriginal and Torres Strait Islander children (5 days [CI 5-6]) was four days longer than other Australian children (1 day [CI 1-1]). Aboriginal and Torres Strait Islander children in the registry were more likely to be male (61.8%), children ≤4 years of age (60.0%), live in outer regional

[q] Discharge Ratio – Hazard Ratio for survival time, where survival time is LOS.

areas (28.9%), from very low SES backgrounds (51.2%), and with burns caused from scalds (39.4%). For these children partial thickness burns (75.7%) and %TBSA below 10 (84.7%) were more prevalent, with common treatments including split skin grafts above 3 percent body surface area (%BSA)(10.9%), excisional debridement (12.2%) and social work or psychology intervention (36.4%)(Supplementary File 3 – Table C). Other Australian children in the registry had similar demographics and injury severity, however higher proportions of burns were apparent in other Australian children residing in metropolitan locations (61.0%), from very low SES backgrounds (25.1%), primary burns cause of scalds (51.0%), common treatment of split skin grafts below 3 %BSA (11.9%), and social work or psychology intervention (25.8%).

	Aboriginal & Torres Strait Islander (n = 723, 10.4%)		**Other Australian (n = 6257, 89.6%)**	
Variable	**Count**	**Percentage (Confidence Intervals)**	**Count**	**Percentage (Confidence Intervals)**
Gender*				
Female	276	38.2 (34.7-41.8)	2443	39.0 (37.8-40.3)
Male	447	61.8 (58.2-65.3)	3812	60.9 (59.7-62.1)
Age				
< 1 Years	50	6.9 (5.3-9.0)	744	11.9 (11.1-12.7)
1-4 Years	384	53.1 (49.5-56.7)	3310	52.9 (52.7-54.1)
5-9 Years	154	21.3 (18.5-24.4)	1072	17.1 (16.2-18.1)
10-15 Years	135	18.7 (16.0-21.7)	1131	18.1 (17.1-19.1)
Accessibility/Remoteness Index of Australia				
Metropolitan (RA1)	173	23.9 (21.0-27.2)	3819	61.0 (59.8-62.2)
Inner Regional (RA2)	108	14.9 (12.5-17.7)	1571	25.1 (24.1-26.2)
Outer Regional (RA3)	209	28.9 (25.7-32.3)	677	10.8 (10.1-11.6)
Remote (RA4)	121	16.7 (14.2-19.6)	132	2.1 (1.8-2.5)
Very Remote (RA5)	113	15.6 (13.2-18.5)	58	0.9 (0.7-1.2)
Index of Relative Socio-Economic Advantage and Disadvantage				
Very Low: 1-2	370	51.2 (47.5-54.8)	1571	25.1 (24.1-26.2)
Low: 3-4	152	21.0 (18.2-24.1)	1175	18.8 (17.8-19.8)
Medium: 5-6	91	12.6 (10.4-15.2)	1410	22.5 (21.5-23.6)
High: 7-8	66	9.1 (7.2-11.5)	975	15.6 (14.7-16.5)
Very High: 9-10	44	6.1 (4.6-8.1)	1125	18.0 (17.1-19.0)
STAGE 2: INJURY CAUSE				
Scald	285	39.4 (35.9-43.0)	3192	51.0 (49.8-52.3)
Contact	229	31.7 (28.4-35.2)	1587	25.4 (24.3-26.5)
Flame	141	19.5 (16.8-22.6)	662	10.6 (9.8-11.4)
Friction	29	4.0 (2.8-5.7)	519	8.3 (7.6-9.0)
Other**	39	5.4 (4.0-7.3)	296	4.7 (4.2-5.3)
STAGE 3: INJURY SEVERITY				
Total Body Surface Area %				

Unknown	26	3.6 (2.5-5.2)	203	3.3 (2.8-3.7)
< 10%	612	84.7 (81.8-87.1)	5450	87.1 (86.3-87.9)
10-19%	61	8.4 (6.6-10.7)	461	7.4 (6.8-8.0)
> 19%	24	3.3 (2.2-4.9)	147	2.4 (2.0-2.9)
Depth of Injury				
Superficial Thickness	63	8.7 (6.7-11.0)	695	11.1 (10.4-11.9)
Partial Thickness	547	75.7 (72.4-78.6)	4839	77.3 (76.3-78.4)
Full Thickness	113	15.6 (13.2-18.5)	723	11.6 (10.8-12.4)
Bacterial Infection				
Streptococcus	65	9.0 (7.1-11.3)	131	2.1 (1.8-2.5)
Staphylococcus	104	14.4 (12.0-17.1)	497	7.9 (7.3-8.6)
STAGE 4: TREATMENT				
Treatment – Dressing				
< 10% Body Surface Area	83	11.5 (9.2-13.8)	884	14.1 (13.3-15.0)
≥ 10% Body Surface Area	35	4.8 (3.3-6.4)	237	3.8 (3.3-4.3)
Treatment – Debridement				
Nonexcisional	36	5.0 (3.4-6.6)	256	4.1 (3.6-4.6)
Excisional	88	12.2 (8.9-15.5)	702	11.2 (10.2-12.3)
Treatment - Split Skin Graft				
< 3% Body Surface Area	61	8.4 (6.4-10.5)	742	11.9 (11.1-12.7)
> 3%† Body Surface Area	79	10.9 (7.1-14.8)	455	7.3 (6.2-8.3)
Treatment - Allied Health Intervention				
Physical/OT Therapy	235	32.6 (29.2-36.1)	1355	21.7 (20.6-22.7)
Social Work & Psychology	262	36.4 (32.9-39.9)	1614	25.8 (24.7-26.9)
Other†† Allied Health	147	20.5 (17.5-23.4)	963	15.4 (14.5-16.3)

* Gender X - Intersex/indeterminate not included in table, < 0.00%. **Other: electrical, chemical, no cause recorded. † grafting as <3% includes 3-6, 6-9, 9-12, 12-15, 15-20, 20-30…>80%. †† Other: dietetics, speech pathology, audiology, prosthetics, orthotics, pharmacy. OT – Occupational Therapy

Table 18: Patient characteristics table

Prognostic Factors

Survival Hazard Estimates

Inverse survival hazards estimates (Figure 15) demonstrated Aboriginal and Torres Strait Islander children remain in hospital for longer periods as compared to other Australian children.

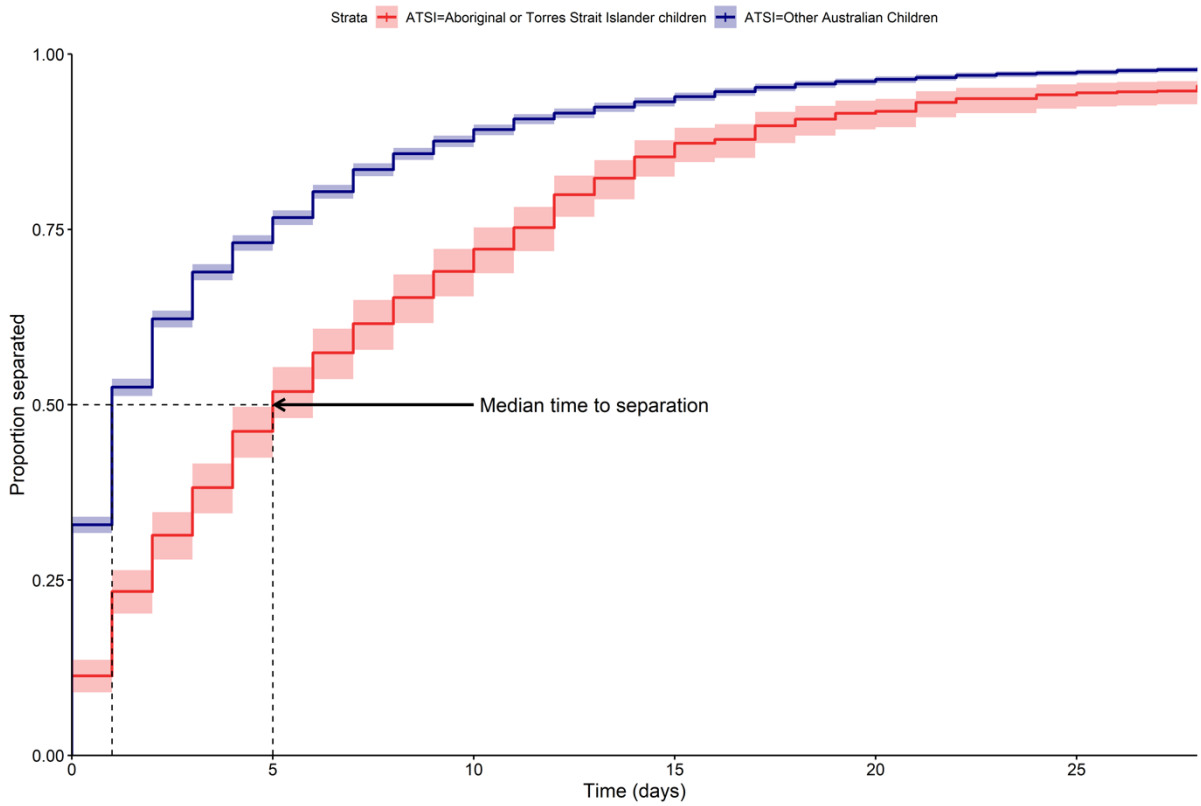


Figure 15: Kaplan-Meier estimates for hospital discharge across both child groups.

Staged Cox Regression Model

Age and SES (Stage 1) had no impact on LOS for Aboriginal and Torres Strait Islander children across all stages of the model (Table 19). Male gender, injury severity and injury treatment increased hospital LOS for Aboriginal and Torres Strait Islander patients. Aboriginal and Torres Strait Islander children from 'outer regional' to 'very remote' areas had 30-60% longer hospital LOS than metropolitan children, with discharge ratios of 1.3 (CI 1.0-1.6) to 1.6 (CI 1.2-2.1). When adding injury cause, severity and treatment to the model, LOS increased for these children, with discharge ratios of 1.8 (CI 1.4-2.3) to 2.6 (CI 1.9-3.5). Similarly, remote ARIA residency increased LOS for other Australian children, although metropolitan residency was associated with reduced LOS, as compared to inner regional to very remote residency, across all model stages (Table 19). Other Australian children who resided in high SES areas had slightly longer LOS across all model stages, for residence in middle SES regions an elevated LOS was evident for injury cause and severity.

Aboriginal & Torres Strait Islander Children				
Discharge Ratio:	**Stage 1 Patient characteristics**	**Stage 2 Injury Cause**	**Stage 3 Injury Severity**	**Stage 4 Treatment**
Gender				
Male	1.1 (0.9 - 1.3)	1.1 (0.9 - 1.2)	**1.1 (1.0 - 1.3)**	1.2 (1.0 - 1.4)
Female	Reference	Reference	Reference	Reference
Age Range				
Less than 1 year	1.1 (0.8 - 1.6)	**1.4 (1.0 – 2.0)**	1.0 (0.7 - 1.4)	1.00 (0.7 - 1.4)
1 to 4 years	0.9 (0.7 - 1.1)	1.0 (0.8 - 1.2)	0.9 (0.7 - 1.1)	0.9 (0.7 - 1.1)
5 to 9 years	1.1 (0.9 - 1.4)	1.1 (0.8 - 1.4)	0.9 (0.7 - 1.2)	0.9 (0.7 - 1.2)
10 to 15 years	Reference	Reference	Reference	Reference
Remote Area Index				
Metropolitan (RA1)	Reference	Reference	Reference	Reference
Inner Regional (RA2)	1.0 (0.8 - 1.3)	1.1 (0.8 - 1.4)	1.0 (0.7 - 1.3)	1.0 (0.7 - 1.3)
Outer Regional (RA3)	**1.3 (1.0 - 1.6)**	**1.3 (1.1 - 1.6)**	**1.5 (1.2 - 1.9)**	**1.8 (1.4 - 2.3)**
Remote (RA4)	**1.7 (1.3 - 2.2)**	**1.8 (1.4 - 2.3)**	**1.9 (1.5 - 2.5)**	**2.4 (1.9 - 3.2)**
Very Remote (RA5)	**1.6 (1.2 - 2.1)**	**1.7 (1.3 - 2.3)**	**2.0 (1.5 - 2.7)**	**2.6 (1.9 - 3.5)**
Index of Relative Socio-Economic Advantage and Disadvantage				
Very Low (1-2)	1.2 (0.9 - 1.7)	1.2 (0.8 - 1.6)	0.9 (0.7 - 1.3)	0.9 (0.6 - 1.3)
Low (3-4)	1.1 (0.8 - 1.6)	1.1 (0.8 - 1.6)	0.9 (0.6 - 1.3)	0.9 (0.6 - 1.3)
Middle (5-6)	1.0 (0.7 - 1.4)	0.9 (0.6 - 1.3)	0.8 (0.5 - 1.1)	0.8 (0.5 - 1.1)
High (7-8)	1.1 (0.7 - 1.6)	1.0 (0.7 - 1.5)	0.8 (0.5 - 1.1)	0.8 (0.5 - 1.2)
Very High (9-10)	Reference	Reference	Reference	Reference
Other Australian Children				
Gender				
Male	1.0 (0.9 - 1.0)	1.0 (0.9 - 1.0)	0.9 (0.9 - 1.00)	1.0 (0.9 - 1.0)
Female	Reference	Reference	Reference	Reference
Age Range				
Less than 1 year	0.9 (0.8 - 1.0)	1.0 (0.9 - 1.2)	1.0 (0.9 - 1.1)	1.0 (0.9 - 1.1)
1 to 4 years	0.9 (0.8 – 1.0)	1.0 (0.9 - 1.1)	1.0 (0.9 - 1.0)	0.9 (0.9 - 1.0)
5 to 9 years	1.0 (0.9 - 1.1)	**1.0 (1.0 - 1.1)**	1.0 (0.9 - 1.1)	1.0 (0.9 - 1.1)
10 to 15 years	Reference	Reference	Reference	Reference
Remote Area Index				
Metropolitan (RA1)	Reference	Reference	Reference	Reference
Inner Regional (RA2)	**1.1 (1.1 - 1.2)**	**1.2 (1.1 - 1.3)**	**1.2 (1.1 - 1.3)**	**1.2 (1.1 - 1.3)**
Outer Regional (RA3)	**1.4 (1.3 - 1.5)**	**1.5 (1.3 - 1.6)**	**1.6 (1.4 - 1.7)**	**1.5 (1.4 - 1.7)**
Remote (RA4)	**1.6 (1.3 - 1.9)**	**1.7 (1.5 - 2.1)**	**1.9 (1.6 - 2.2)**	**1.9 (1.6 - 2.3)**
Very Remote (RA5)	**1.6 (1.2 - 2.1)**	**1.9 (1.5 - 2.5)**	**2.2 (1.7 - 2.9)**	**2.2 (1.7 - 2.9)**
Index of Relative Socio-Economic Advantage and Disadvantage				
Very Low (1-2)	**1.1 (1.0 - 1.2)**	1.0 (0.9 - 1.1)	1.0 (0.9 - 1.1)	0.9 (0.9 - 1.0)
Low (3-4)	**1.0 (1.0 - 1.1)**	1.00 (0.9 - 1.1)	1.0 (0.9 - 1.1)	0.9 (0.9 - 1.0)
Middle (5-6)	**1.1 (1.0 - 1.2)**	**1.1 (1.0 - 1.1)**	**1.0 (1.0 - 1.1)**	1.0 (0.9 - 1.1)
High (7-8)	**1.1 (1.0 - 1.2)**	**1.1 (1.0 - 1.2)**	**1.1 (1.0 - 1.2)**	**1.1 (1.0 - 1.2)**
Very High (9-10)	Reference	Reference	Reference	Reference

Note: Discharge ratios is the hazard ratio. A discharge ratio > 1.0 signifies a statistically significant longer LOS over the reference variable.

Table 19: Discharge ratio to Patient Demographics

Flame, as compared to scald burns (Stage 2), had the highest discharge ratio for both Aboriginal and Torres Strait Islander children and other Australian children (Table 20). This significance remained even after controlling for injury severity and treatment.

Aboriginal & Torres Strait Islander Children			
Discharge Ratio:	**Stage 2 Injury Cause**	**Stage 3 Injury Severity**	**Stage 4 Treatment**
Primary Burn Cause			
Scald	Reference	Reference	Reference
Contact	0.9 (0.7 - 1.0)	1.0 (0.8 - 1.2)	1.0 (0.8 - 1.2)
Flame	**1.6 (1.3 - 2.0)**	**1.3 (1.0 - 1.6)**	**1.3 (1.0 - 1.6)**
Other	1.0 (0.7 - 1.3)	1.0 (0.7 - 1.4)	1.1 (0.8 - 1.5)
Other Australian Children			
Primary Burn Cause			
Scald	Reference	Reference	Reference
Contact	0.7 (0.7 - 0.8)	0.8 (0.8 - 0.9)	0.9 (0.8 – 1.0)
Flame	**1.6 (1.5 - 1.8)**	**1.1 (1.0 - 1.2)**	**1.1 (1.0 - 1.2)**
Other	0.8 (0.7 - 0.9)	0.9 (0.8 - 0.9)	1.0 (0.9 - 1.0)
Other: electrical, chemical, no cause recorded.			

Table 20: Discharge ratio to Injury Cause

For factors related to injury severity (Stage 3), presence of Staphylococcus sp. infection and full thickness burns increased LOS for Aboriginal and Torres Strait Islander children (Table 20). After controlling for treatment, only full thickness burns remained as significant factors in the model. The greatest discharge ratio for Aboriginal and Torres Strait Islander children was %TBSA, with a discharge ratio of 2.6 (CI 1.9-3.5) for burns 10-19 %TBSA and 5.1 (CI 3.1-8.3) for burns greater than 19 %TBSA, as compared to burns less than 10 %TBSA. Discharge ratios decreased for %TBSA, after controlling for different treatments, with significance remaining. Similar discharge ratios were evident in other Australian children for %TBSA. Both Streptococcus sp. and Staphylococcus sp. infections significantly increased discharge ratios for other Australian children, which remained after controlling for treatment (Table 21).

Aboriginal & Torres Strait Islander Children			Other Australian Children	
Discharge Ratio:	**Stage 3 Injury Severity**	**Stage 4 Treatment**	**Stage 3 Injury Severity**	**Stage 4 Treatment**
% Total Body Surface Area Range				
Below 10%	Reference	Reference	Reference	Reference
10% to 19%	**2.6 (1.9 - 3.5)**	**2.2 (1.6 - 3.1)**	**2.2 (2.0 - 2.5)**	**2.0 (1.8 - 2.2)**
Greater than 19%	**5.1 (3.1 - 8.3)**	**4.0 (2.3 – 7.0)**	**5.3 (4.4 - 6.4)**	**5.0 (4.0 - 6.1)**
Burn Depth				
Superficial Thickness	Reference	Reference	Reference	Reference
Partial Thickness	1.3 (0.9 - 1.7)	1.1 (0.8 - 1.5)	0.8 (0.7 - 0.9)	0.8 (0.7 - 0.9)
Full Thickness	**2.0 (1.4 - 2.9)**	**1.8 (1.2 - 2.6)**	1.0 (0.9 - 1.2)	**1.1 (1.0 - 1.3)**
Bacterial Infection				
No	Reference	Reference	Reference	Reference
Streptococcus	1.3 (0.9 - 1.8)	1.2 (0.8 - 1.7)	**1.5 (1.3 - 1.8)**	**1.4 (1.2 - 1.7)**
Staphylococcus	**1.4 (1.1 - 1.8)**	1.2 (0.9 - 1.5)	**1.4 (1.3 - 1.5)**	**1.3 (1.1 - 1.4)**

Table 21: Discharge ratio to Injury Severity

Stage 4 Treatment		
Discharge Ratio:	**Aboriginal and Torres Strait Islander**	**Other Australian**
Burn Dressing		
No	Reference	Reference
Less than 10%	**1.4 (1.0 - 1.9)**	**1.1 (1.0 - 1.2)**
Greater than 10%	1.4 (0.9 - 2.3)	1.0 (0.9 - 1.2)
Sedation		
No	Reference	Reference
Yes	0.9 (0.6 - 1.2)	1.0 (0.9 - 1.1)
Burn Debridement		
No	Reference	Reference
Non Excisional	**1.5 (1.0 - 2.2)**	**1.3 (1.2 - 1.5)**
Excisional	**1.3 (1.0 - 1.8)**	**1.3 (1.2 - 1.4)**
Split Skin Graft		
No	Reference	Reference
Less than 3%	**1.6 (1.1 - 2.2)**	1.0. (0.9 - 1.1)
Greater than 3%	**2.0 (1.5 - 2.8)**	**1.6 (1.5 - 1.8)**
Allied Health Intervention		
No	Reference	Reference
Yes	**1.6 (1.3 - 2.1)**	**2.2 (2.1 - 2.4)**
Allied Health: physiotherapy, occupational therapy, social work, psychology, dietetics, speech pathology, audiology, prosthetics, orthotics, pharmacy		

Table 22: Discharge ratio to Treatment

Factors relating to treatment (Stage 4) including allied health intervention, burn dressings less than 10%TBSA and any burn debridement or split skin graft were significantly associated with discharge ratios for Aboriginal and Torres Strait Islander children (Table 22). The highest treatment discharge ratio for Aboriginal and Torres Strait Islander children was for split skin grafts above 3%BSA (2.0 [CI 1.5-2.8]), as compared to children without this treatment. Similar results were evident in other Australian children, with the greatest discharge ratio found in children who had an allied health intervention (2.2 [2.1-2.4])(Table 22).

5.6 Discussion

In this study, Aboriginal and Torres Strait Islander children had a median hospital LOS of five days, which is longer than the four days previously reported [51, 53, 62, 69]. We also found that Aboriginal and Torres Strait Islander children had a hospital LOS four days longer than other Australian children, compared to the past reporting of three days [51, 53, 62, 63, 69]. These extra days of hospital stay represent additional burden on Aboriginal and Torres Strait Islander families not previously captured, be that through OOPHE, treatment severity, isolation, re-traumatisation, strain on family connections and may be associated with poorer function and health-related quality of life [103].

Aboriginal and Torres Strait Islander children from very remote locations had longer hospital LOS than metropolitan children and LOS was also impacted by primary burns cause (flame versus scald), greater injury severity and various treatment factors (split skin graft, burn debridement, allied health intervention). Similar findings were observed in other Australian children, however the proportion of children residing in rural and remote locations and discharge ratios were greater overall for Aboriginal and Torres Strait Islander children. Longer hospital LOS for burns injury admissions have previously been reported in rural and remote Australia and a range of factors are likely to contribute to this, such as access to appropriate health services [63, 71, 364]. In these settings, major challenges remain for Aboriginal and Torres Strait Islander people and other Australians in the delivery of healthcare, including high costs, limited resources, varying staff retention, training access and most rural and remote clinical staff being trained as generalists [364-366]. These factors may all directly impact on both first aid and treatment of serious burns injuries.

The majority of remote communities are reliant on small local health centres, general practices and/or community controlled or Aboriginal specific services. These local services may consist of on-call nursing staff and Aboriginal Health Workers who may be the main point of call for several communities over vast geographical locations. These services are restricted in the treatment and expertise they can provide for serious burns. Serious burns require air retrieval or ambulance transfer to more specialised tertiary facilities. Transport services are impacted by availability, weather conditions and other factors. Additionally, decreased capacity to access appropriate burns first aid treatment has been reported in remote Australia [79]. In these settings, access to cool, clean running water can be impacted by inadequate community infrastructure. All of these elements disadvantage access to best practice treatment options for serious burns. For instance, skin substitute Biobrane™ has an optimal application window from the time of burn occurrence [367, 368].

Issues of remoteness may be further compounded by community and cultural obligations. For example, Aboriginal and Torres Strait Islander families may travel away from home or to remote locations for sorry business[r], visiting communities or camping where running water may not exist [79]. We found that flame burns increased hospital LOS for Aboriginal and Torres Strait Islander children. Compared to other causative mechanisms, flame burns typically are of

[r] Sorry business – cultural, spiritual and social responsibilities, obligations and ceremonies associated with death in Aboriginal and Torres Strait Islander communities.

greater thickness, there is an increased risk of infection and severity and can require intense and invasive surgical intervention which increases LOS. Past reporting has found a higher incidence of more invasive treatment, ie skin grafting in Australian children from rural locations as compared to metropolitan areas [71]. We found that split skin grafts increased LOS for Aboriginal and Torres Strait Islander children in this study, which is different to past research in other populations which reported grafting as decreasing LOS in children [47]. Recent research has suggested that Aboriginal and Torres Strait Islander children are remaining longer in hospital for their burns treatment, due to perceived social issues from clinical teams and for easier access to multidisciplinary support and care i.e. allied health support [351]. However, while we found allied health intervention was proportionally greater in Aboriginal and Torres Strait Islander children, higher discharge ratios were found in other Australian children with allied health intervention. This is at odds with the rationale that LOS is increased to improve access to multidisciplinary support. These outcomes are also different to recent poisoning research, suggesting similar allied health contact levels between Aboriginal and other Australian children [369].

The most significant prognostic factor providing the highest discharge ratios in all children was %TBSA, similar to previous research [47, 63-65, 71, 80, 357, 359-362]. In Aboriginal and Torres Strait Islander children, greater %TBSA levels have been reported to increase LOS, however our ratios were greater than previous reports [63]. Full thickness burns was another prognostic factor for Aboriginal and Torres Strait Islander children, again in line with past reporting [63]. In adult populations, full thickness burns and bacterial infections have been associated with increased LOS [47, 357, 359-362]. Although Aboriginal and Torres Strait Islander children had a higher proportion of bacterial infection, it was not associated with increased LOS, unlike for other Australian children. It is possible that more Aboriginal children have bacterial infections as an underlying comorbidity, potentially representing differentials in environment and living conditions (ie poverty), or barriers to accessing health services or the provision of culturally responsive healthcare treatment [370]. This can have significant impacts on health later in life, including renal disease [346].

There are also additional factors which could contribute to increases in hospital LOS for Aboriginal and Torres Strait Islander children, which BRANZ does not currently record. There is a 'remote-alisation' and over-medicalisation of Aboriginal and Torres Strait Islander children [138, 309, 351] where the Australian healthcare system inadvertently fosters implicit bias, systemic

racism, power imbalances and racialisation of Aboriginal and/or Torres Strait Islander identity with presumptive beliefs on remoteness [138, 143, 309, 351, 371, 372]. These presumptive beliefs modify the diagnostic reasoning process for clinicians when working with Aboriginal and Torres Strait Islander children and their families and may potentially (and unintentionally) result in longer hospital LOS in Aboriginal and Torres Strait Islander children with a burns injury [138, 309, 351]. Further, burns care continues to be based on Western biomedical paradigms, predominantly focussing on the clinical characteristics of the burns injury with less emphasis on the psychosocial aspects [351, 373, 374]. This is disconnected to Aboriginal and Torres Strait Islander models of health and well-being, which are holistic and interconnected, encompassing the child, their family and community [6, 7, 9, 355, 375]. Clinical teams should work with families in regard to their needs and obligations, with support from Aboriginal Healthcare Workers (AHW) and local health services, so that hospital LOS for treatment can be appropriately managed. Collaborative, family-centred actions such as this act to alleviate stress and burden on Aboriginal and Torres Strait Islander families, which in turn facilitates a child achieving wellbeing [375-377].

In this study, rural residency, burns severity (flame, high %TBSA, full thickness burns) and complex treatment (split skin grafts) are prognostic factors contributing to increased hospital LOS for Aboriginal and Torres Strait Islander children. These factors are also health inequities, as greater proportions of Aboriginal and Torres Strait Islander children are impacted, compared to other Australian children. Remote Aboriginal and Torres Strait Islander children who suffer a complex burn have reduced or delayed access to healthcare for burns treatment and rehabilitation, creating longer hospital LOS. Adding in factors such as low SES, also more prevalent in this cohort, is likely to lead to additional financial burden from OOPHE, which can create isolation and impact on recovery [155, 378-381]. Such factors can be further compounded by culturally unsafe healthcare, which creates a lack of autonomy or self-determination in the treatment and decision-making process for Aboriginal and Torres Strait Islander families [351]. Specialised burns services should actively work to counteract LOS as a health inequity manifestation, through staff training in cultural safety and reflexivity as a minimum standard, along with tertiary services establishing quality indicators of cultural safety [382]. A review of government policies and initiatives designed to address the needs of rural Aboriginal and Torres Strait Islander patients, such as the Patient Assisted Travel Scheme (PATS), may also be warranted, with consideration of unavoidable and excessive LOS for patients from low SES.

Strengths and Limitations

Strengths include our use of nine years of national data, with a focus on LOS prognostic factors for Aboriginal and Torres Strait Islander children. Our use of Indigenous research methodology and methods (Figure 14) approach to missing data and focus on health inequities provides a greater appreciation of the depth and breadth of burn injuries present in Aboriginal and Torres Strait Islander children.

This analysis has some limitations. SES was defined based on neighbourhood postcode and may not be a true representation [358]. The BRANZ captures data from reporting hospitals only (generalist hospitals are not included) and not all hospitals have been reporting for the same length of time. BRANZ is a Western biomedically constructed, epidemiological repository where colonial constraints and whiteness are present and unacknowledged [83, 330]. Under-identification of Aboriginal and Torres Strait Islander children is not unusual in registries of this type [63, 354]. Further to this, the BRANZ uses International Classification of Disease codes which do not code for ALO, Aboriginal Health Workers, AHP or Aboriginal Traditional Healers, despite coding for other interventions such as 'Spiritual Care' under 'Allied Health' [383]. If these data were recorded it would provide significant insights into the relationship between Aboriginal and Torres Strait Islander healthcare practice and models of care with hospital LOS. In order to capture data that appropriately records factors impacting on patient outcomes, data registries should engage with Aboriginal and Torres Strait Islander health bodies to broaden coding, to capture community needs and work towards data sovereignty. Data which recognises and responds to the health and well-being concepts and needs of Australia's First Peoples is a step towards data sovereignty for Aboriginal and Torres Strait Islander communities [84, 145]. An example of this includes the Footprints in Time Study, highlighting Indigenous leadership, oversight and a focus on positive strengths-based data collection and reporting [355].

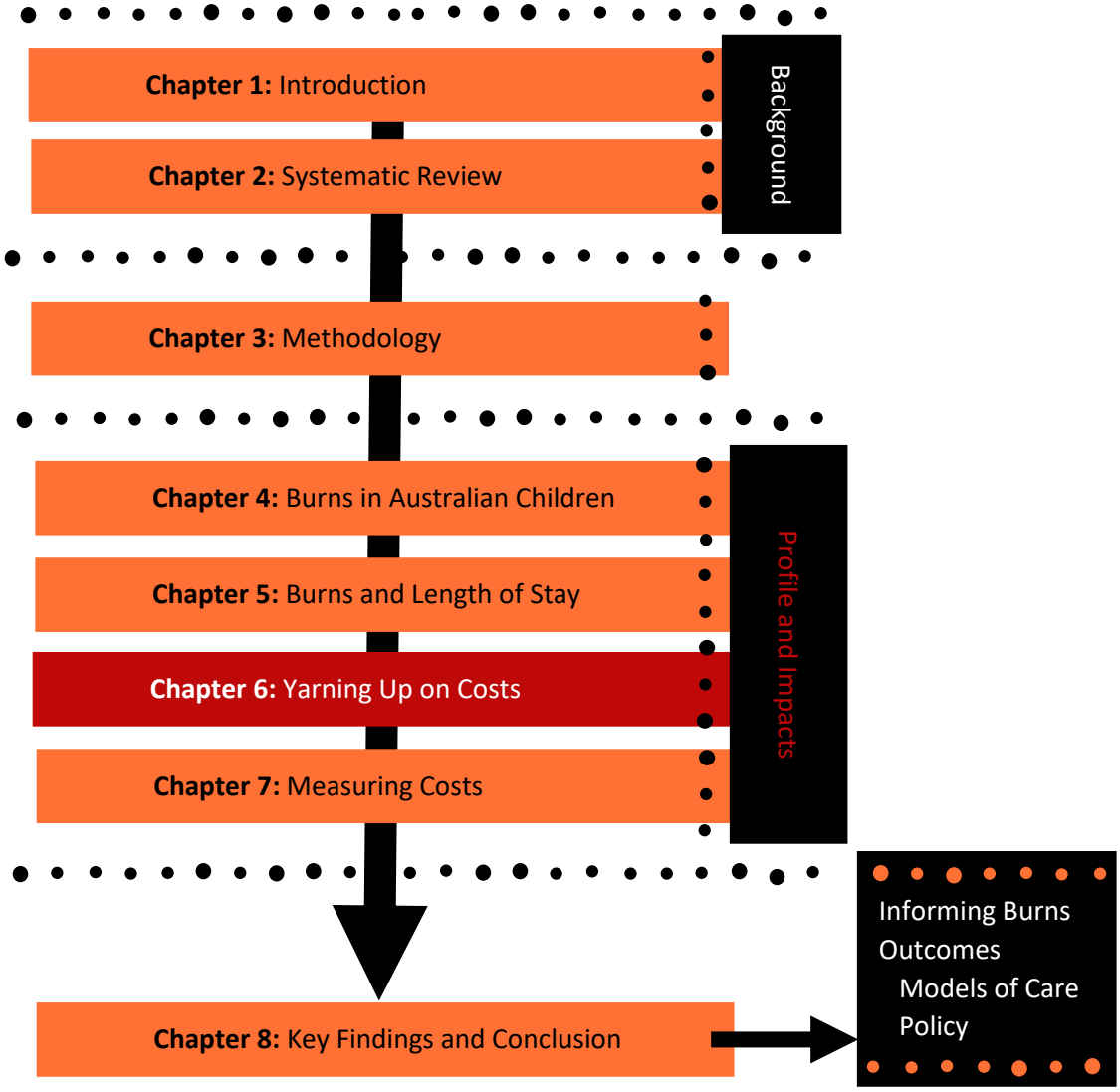
5.7 Conclusion

Remoteness, %TBSA, flame and full thickness burns are prognostic factors creating greater LOS in hospital burns admissions for Aboriginal and Torres Strait Islander children. This health inequity introduces additional and unique burdens on these families, including financial hardship, isolation and a lack of autonomy. Burdens which can be exacerbated by racism and whiteness, thus impacting negatively on an Aboriginal and/or Torres Strait Islander child's well-being. The complexities and uniqueness of these burdens needs to be considered in burns data repositories, clinical models of care, policies and targeted burns interventions for prevention

and treatment in Aboriginal and Torres Strait Islander communities. Aboriginal and Torres Strait Islander families experiencing significant hospital LOS warrant further support (emotionally/financially/socially) to decrease the risk of further marginalisation.

CHAPTER 6

Yarning Up on Out-of-Pocket Healthcare Expenditure



6.1 Preamble

Remote residency, flame burns, high %TBSA and full thickness burns are prognostic factors which contribute to an increase in LOS for all Australian children. As Chapter 5 identified, these prognostic factors are greater in Aboriginal and Torres Strait Islander children than other Australian children. As health inequities, they impact on Aboriginal and Torres Strait Islander children, providing a much longer hospital LOS for their burns injuries - four days greater than for other Australian children. Longer hospital LOS has the ability to impact on families as a whole, as a result of OOPHE, especially for families who are financially constrained through lower SES. Chapter 4 identified that 'low' to 'very low' SES was greater in Aboriginal and Torres Strait Islander children with an acute burns injury, as compared to other Australian children. The relationship of these health inequities and their ability to interact, creating financial hardship on Aboriginal and Torres Strait Islander families from OOPHE, remains largely unexplored. This chapter is original research, examining OOPHE on a small sample of Aboriginal families whose child has had an acute burns injury. The main findings in this scoping exploration were used to redesign and psychometrically assess an OOPHE survey for Aboriginal and Torres Strait Islander families in Chapter 7; they are also used to inform recommendations in Chapter 8.

This chapter been accepted for publication in the Australian and New Zealand Journal of Public Health.

Ryder, C., Mackean, T., Hunter, K., Coombes, J., Holland, A.J.A., and Ivers, R., Yarning Up About Out-of-Pocket Healthcare Expenditure in Burns with Aboriginal Families.

Corresponding Author: Courtney Ryder

Accepted: 3 January 2021

6.1.1 Summary: Decolonising Methodology

> *"Decolonisation...recognises that we all as researchers … bring our own world views and perspectives, as a lens to gaze and explore what we read about, think about, research and discuss".*
>
> Juanita Sherwood [144(p. 28)]

This is the only study in this dissertation which did not engage with knowledge interface and quantitative research methodologies. For these reasons, the knowledge interface methodology, of weaving a research interface, was not used for this study. Instead, decolonisation methodology was used. Decolonisation as a methodology engages with

processes of power, knowledge and truth generated through colonisation and imperialism, where decolonisation seeks to challenge this all-encompassing and hidden whiteness, acting to counteract and reverse these processes [288]. As a methodology for researchers, this must occur throughout the research process; for researchers this can be challenging, especially for First Nations and Aboriginal researchers such as myself, as we seek to understand the nuanced impacts of colonisation on our thinking processes, being able to critically examine and unpack how they were created and reinforced so that we can counteract this process and decolonise our minds for research [288].

Out-of-pocket costs as related to healthcare is not a particularly new concept. As a term, it has appeared commonly throughout academic literature and can be traced back to articles over a century ago:

> *"Dr. H. Woods established a fund to repay my out-of-pocket expenses, and so refunded me £50".*
>
> Robert R Rentoul [384(p. 759)]

The above excerpt is taken from an article in the British Medical Journal in 1896, calling for support to fund Midwifery Expenses under the Midwifery Bill [384]. Although focussed on the OOPHE of practising health professionals, this article assists in highlighting the systems of knowledge which underpin OOPHE. As a term, OOPHE comes from imperial (colonised) systems of knowledge and Western biomedical constructs and understandings. As such, OOPHE is subjective, having been established from imperial systems of knowledge; these systems define the truth and knowledge of OOPHE, they also maintain power and control through [288]:

1. Classifying of OOPHE
2. Defining experiences of OOPHE
3. Comparisons of OOPHE
4. Evaluations surrounding OOPHE.

As described in Chapter 3, these processes allow a Western/Eurocentric hegemony to prevail in defining how we as First Nations peoples should see, react, interact and experience OOPHE [288]. For these reasons, it was imperative to engage with a decolonisation methodology which employs decolonisation research methods in this study. Decolonised research methods employed in this study included:

Yarning

As defined in Chapter 3, as a process, Yarning with Aboriginal families in this study provided participants with complete control over sharing their lived experiences of OOPHE.

Trust and Relationships

Prior to the Yarning sessions with participants, it was important for me as an Aboriginal researcher to build a relationship with participants so that they would feel comfortable discussing OOPHE with me, but also have trust in me in recording and using their OOPHE experiences for this research.

No Assumptions

While prompting questions were created to start the Yarning sessions with participants, they were designed with a decolonisation lens which did not make assumptions on the OOPHE experiences of Aboriginal families. Additionally, while a thematic process was used in NVivo to code OOPHE themes from Yarning sessions, a decolonisation approach was used in this coding, where no prior OOPHE definitions and assumptions were employed to code these themes.

6.2 Abstract

Background: This study sought to understand the impact of out-of-pocket healthcare expenditure (OOPHE) on Aboriginal families of children with acute burns injury.

Methods: Families participating in a larger Australia wide study on burns injuries in Aboriginal and Torres Strait Islander children were approached to participate. Decolonising methodology and yarning were employed with participants, to scope OOPHE for burns care. Thematic analyses were used with transcripts and data organised using qualitative analysis software (NVivo, Version 12).

Results: Six families agreed to participate. Four yarning sessions were undertaken, across South Australia, New South Wales and Queensland. The range of OOPHE identified included: costs (ie transport, pain medication, bandages), loss (ie employment capacity, social and community), and support (ie family, service support). The need to cover OOPHE significantly impacted on participants, from restricting social interactions to paying household bills. Close family connections and networks were protective in alleviating financial burden.

Conclusion: OOPHE for burns care financially impacted Aboriginal families. Economic hardship was reported in families residing rurally or with reduced employment capacity. Family and network connections were mitigating factors for financial burden.

Implications for Public Health: Targeted support strategies are required to address OOPHE in burns related injuries for Aboriginal communities.

6.3 Introduction

Internationally, 100 million people are forced below the poverty line from healthcare spending [157, 385]. The majority of these people reside in low to middle income countries, however individuals from high-income countries are also impacted [155-157, 385]. In Australia, a patient's OOPHE healthcare spending has progressively increased [155]. OOPHE are expenses related to health conditions which are not covered by universal taxpayer-funded healthcare or private health insurance. These expenses include direct costs, gap payments, transportation, pharmaceutical costs or equipment purchases for home - as well as indirect costs such as carers taking time away from the labour force to care, resulting in a loss of household income. When households need to increase expenditure on healthcare, disposable income is reduced. Households without savings use a variety of mechanisms to cope, including borrowing money, selling assets and forgoing general necessities [157, 378]. This can cause catastrophic health expenditure, creating severe economic hardship for families, even bankruptcy [155-157, 385]. In these cases, households make significant choices between family well-being or financial

survival [155, 379]. This can result in households avoiding or delaying medical treatment as a financial survival strategy [155, 379, 386]. Households in rural and remote settings face additional OOPHE burden through travel for healthcare, additionally these households are more likely to be in low income brackets [386, 387]. In Australia, recent research has demonstrated that families in low income brackets are the most vulnerable to catastrophic health expenditure [386].

Aboriginal people make up 3% of the Australian population and continue to experience the impact of colonisation, which manifests as ongoing dispossession and marginalisation [355, 388]. This is evident across multiple social and health inequities (ie employment, education, life expectancy and infant mortality)[9, 312]. Burn incidence and severity is another example of a health inequity for Aboriginal children, with hospitalisation rates 2-3 times greater than for other Australian children [63, 67, 75]. This is currently being explored in the Coolamon study [75]. This paper aims to explore OOPHE for acute burns injuries with a cohort of Coolamon study families.

6.4 Methods

In Australia, a tool exploring OOPHE has been developed; however, its focus is on general populations, particularly older people with a chronic condition [156, 157]. There has not been an OOPHE exploration of Aboriginal and Torres Strait Islander families. We sought to examine preliminary perspectives and experiences of OOPHE for acute burns injuries with a sample of Coolamon study families. A decolonising methodology was engaged to focus this study away from colonising constructs and existing dominant knowledge on OOPHE [285]. This was focussed over three main areas of 1. Yarning, 2. Trust and Relationships and 3. No Assumptions. Yarning, a conversational research method for data collection, was employed with Aboriginal families by the Aboriginal research (Courtney Ryder) to centralise their OOPHE knowledge and maintain integrity of their OOPHE lived experience [2]. All data analyses was conducted by Aboriginal researchers to ensure focus on Indigenous knowledges (knowing, being and doing) [132, 134].

Participants (parents or carers) were drawn from the Coolamon study, if their child had sustained a burn to the face, hands, perineum or burns with a Total Body Surface Area ≥10% that required ≥1 night hospital stay and follow-up care [75]. In this scoping study the sample size was purposely small, to facilitate building strong, supportive relationships and a safe environment which would generate rich data collection during Yarning [2, 285]. Prospective

participants were contacted by Coolamon study research assistants to gauge interest and followed up by Courtney Ryder, who spent time building relationships over the phone in a process controlled by the participant which was imperative to enacting decolonisation of processes (Appendix C, C.1 Study Information Sheet, C.2 Consent Form). Yarning sessions were conducted over the telephone or in-person, with or without family members or Coolamon study research assistants (Appendix C, C.3 Yarning Script). All sessions were recorded, transcribed and de-identified, with NVivo 12 qualitative analysis software (QSR International) used for thematic coding. Participants were provided with feedback on the outcomes of this study through the Coolamon project.

Ethics for this scoping study was approved (Table 23).

Human Research Ethics Committee	State
Aboriginal Health and Medical Research Council	NSW
Sydney Children's Hospitals Network Human Research Ethics Committee	NSW
Townsville Hospital and Health Service Human Research Ethics Committee	QLD
Children's Health Queensland Hospital and Health Service Human Research Ethics Committee	QLD
Human Research Ethics Committee Office of Research Ethics The University of Queensland	QLD
Aboriginal Health Research Ethics Committee	SA
Women's and Children's Health Network Human Research Ethics Committee	SA
Flinders University Human Research Ethics Committee	SA
Central Australian Human Research Ethics Committee	NT
Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research	NT

Table 23: Human Research Ethics Approval for Scoping Study by Jurisdiction

6.5 Results

A total of 31 prospective participants were contacted and eight were happy to be contacted further. From this cohort, two declined and six were recruited to the scoping study with between 3-10 phone calls made prior to Yarning scheduling. Four yarning sessions in total were conducted, three consisting of one participant and Courtney Ryder, the other three: participants, research assistant and Courtney Ryder. The data were arranged into themes summarised in Table 24.

COSTS	LOSS
Initial (Parking, Consumables) Follow-up (Travel, Accommodation, Parking, Extra Treatment, Time) Home (Pharmacy, Clothing, Food, House Utilities)	Money Employment Capacity Social and Community Living Activities Family Support (Isolation)
SUPPORT	**STRAIN**
Family (Partner, Extended) Service Support (Hospital, Government)	Exhaustion - Indigenous Cultural Dimensions (Physical, Psychological, Spiritual, Cultural)

	Cultural Dislocation, Isolation
SIBLINGS	**FINANCIAL STRESS**
Educational Psychological Social	Selling Assets Borrowing Money (Loans/Family) Increased Debt (Credit Cards, Bills)

Table 24: Themes and Sub Themes of OOPHE in Aboriginal families whose child has sustained a burns injury.

COSTS

1. Initial Treatment

During hospitalisation participants reported costs from travel, parking and food. Reporting of limited access to affordable food was common and participants spent hundreds of dollars in hospital cafeterias each week as they felt obligated to stay on the burns ward or in intensive care with their child.

> *"When we went it cost us a fortune in meals … And you want to eat close because you didn't want to go anywhere".*

Feelings of being in crisis were common, where participants did whatever it took to get by. Having family bring in food, or skipping meals, was reported as an alternative to reduce costs while in hospital.

> *"In hospital … I would have like a brunch …. instead of having three meals I would only have two".*

2. Follow Up Treatment

Accommodation, travel and time were common expenses for follow-up treatment (rehospitalisation or outpatients). Participants residing rurally reported major expenses for follow-up treatment, when it was not uncommon for these households to travel over five hours for treatment. This created financial strain for these participants.

> *"Every time we go, we would have to make sure you would have at least $700 just like for the petrol, the food, everything".*

3. At Home

Ongoing treatment and care requirements financially impacted families while as home, through house utilities, pharmacy (prescription/non-prescription), additional clothing and time (personal/family).

> *"You would have to wash the silicone and you would have to wash your bandages, but you have to wash them separately and special …. I mean, it was just … it was costing, because obviously you are running the water. Then it's time consuming".*

Non-prescription treatment for burns, usually a necessity, were also a significant cost but were not covered or subsidised for burns patients. This was difficult for participants on single income or government benefits.

> *"It's not subsidised at all. I needed sterilised water for their dressings because I did not get enough at the hospital to carry me, like, tie me over. So, I had to go get that from the chemist. And all the creams and stuff that you have to put on, they're not covered at all".*

> *"Finding it hard just, sometimes, for his bandages that I had to get, you know, because bandages cost $30 and stuff I couldn't just, necessarily, go to the hospital and get new bandages…. and just being on the Centrelink income, sort of, made it hard, as well".*

In these cases, financial stress was evident with participants maxing out credit cards, sacrificing bills or even selling assets to get by.

> *"Because you have to have the money to be able to travel down there, so it was like you just paid the bare minimum of everything".*

LOSS

1. Money

Household income and employment capacity was impacted for participants, especially those who were self-employed or ran family businesses.

> *"I missed, what, six to eight – no ten – I – I had ten months off, all up".*

> *"Yeah. I lost out on a lot of business through that but, you know, that happens."*

Participants did report feeling supported by workplaces to meet the treatment and care needs of their child.

> *"Well, we are quite, both quite lucky … both works have been really flexible".*

2. Social and Community

Social and family activities were impacted. Going without household items, not participating in community events and cancelling holidays were all actions taken to alleviate costs and meet the care requirements.

> *"we didn't have our holiday that we had planned…. luckily, they refunded us the money".*

Participants living away from family networks, or their community, reported feeling isolated and restricted in the types of support they could access. This created additional burden and cost, through juggling family life and treatment.

"So, for the first week and a half I had family up here, but after that.. I'd have to get up early and get the two bigger ones. One wasn't at school yet, so they went to day care and I'd sent my eldest to before school care. So, I would get them there at about quarter to seven".

3. Family Support (Isolation)

Overwhelming feelings of stress, guilt and emotional isolation were reported by participants, where burden was intensified through financial strain.

"It was a split-second decision that changed all our lives"

" while she was in hospital I would be, like, have no idea how I'm getting through"

"always a bit worried that he will .. hurt himself again".

This burden was expressed by siblings as well.

"they started getting, like, very clingy, … it got to the stage where I couldn't even get them to sleep in their own bed. They were just in my bed every night. The minute I was home they had to still be just attached to me".

SUPPORT

1. Family

Family support was a major protective element in decreasing financial stress in families. Participants approached extended family for support to get by.

"Ask family members for, you know, a hand with some money until the next payday, sort of, for your food and your electricity bills and whatever else that come in at the time".

For other participants this was a regular occurrence, where family networks regularly purchased important items.

"Mum and Dad, and my husband's parents would take turns in buying formulas for me, so I didn't have to fork out that much money".

Often participants commented on the significant financial role family networks played in keeping them away from poverty.

"It took probably about four or five months to get everything back on track but as I said, I had my family to help me out when I couldn't do things and most people, either their family aren't in a situation to do that or they wouldn't".

"I had my family to help me out. If I didn't I would have had to sell stuff".

Family networks also assisted in other ways, playing significant caring roles with siblings, in getting through initial and ongoing treatment.

"They had to have him the night before, because I wasn't waking him up and dropping him off at their house before 7 am".

For others, this support was limited, where some reported not being able to ask their family networks for support.

"I could really turn to, like, you know, other than Centrelink or, you know, not for – not for that amount of money, anyway".

Others reported support being one-sided, or not feeling comfortable talking or approaching some family networks for their financial needs.

"I know that if I needed money, I could get money off any of my brothers or sisters and that. But yeah, it's like that they are all in the same boat as me …. They are working to get by as well…. I would rather suffer and not everybody else..".

2. Service Support

Tangible support, not related to family networks, was identified. Some participants reported hospital social workers arranging fuel and cafeteria vouchers.

"I once got a $100 one (fuel voucher) and that one lasted about a week and a half".

On hospital discharge participants reported being provided with supplies until their next visit. In one case, a participant was told by hospital staff to take supplies present in their child's room as it could not be reused.

"She said anything that's in this room, like, all the Hypafix, everything, she goes, take it, because it's open in the room they have to ditch it. She goes, it'll save a lot of money, so just take it".

Others commented on a lack of support, they did not see a social worker, or Aboriginal health worker at hospital. Some reported not being made aware of government initiatives, such as the PATS.

"I didn't see a social worker or anything. Like, I didn't see anyone… I didn't see anyone at the hospital. I sort of got no, sort of, support there. It was just, you have to be here".

Participants also reported struggling with accessing specific government initiatives. One participant reported ineligibility for a carer's pension, because despite the additional care that their child required, because of their age they were deemed as requiring 24-hour care.

"Centrelink have decided because they are under three they are an infant and already in 24 hours care; how is what they need any different".

6.6 Discussion

We found that Aboriginal families have a range of OOPHE costs related to their injured child.

While in hospital most parents felt pressured to stay with their child at all times, which restricted their access to meals. Previous research reports that Australian families can spend over $400 a week for hospital meals and parking [389, 390]. Our participants were impacted financially, reporting exorbitant costs for meals in hospital. To cope, participants would either skip or have family bring in meals. These coping mechanisms have not been reported previously. The link between a child's health and well-being and that of their parent's is well documented and parents are more likely to be physically and mentally at their best when not suffering food insecurity [391]. Social worker intervention was felt by families in our study to be a protective element in this area. Social workers are adept in understanding the effects of hospitalisation on families and are essential for acute paediatric burns admissions in Australia [351].

Engagement in the labour force was negatively impacted for our participants, with all requiring substantial time away from work for initial treatment and ongoing care for their child. Impacts of this nature, for ongoing health requirements have been reported priorly in Aboriginal households [312] and also in other Australian households [156, 157, 390]. A significant positive was that most participants felt supported by their workplace and not insecure in their employment from initial and ongoing treatment for their child. However, self-employed participants did not report this same level of support and these households were financially impacted. Comparable impacts have been reported by other Australian patients or carers who are self-employed [156]. Additional financial support is likely required for household which are in these situations to ensure protection from catastrophic healthcare expenditure.

Costs associated with travel, accommodation and hospital parking were significant for participants and consistent with other Australian OOPHE studies [390, 392]. Participants who resided rurally were further impacted financially, due to greater travel and scheduling requirements to attend follow-up treatment. These outcomes correspond to previous reporting of financial burden and stress for rurally located Aboriginal and Torres Strait Islander families requiring specialised medical care [10, 312]. Our data indicated that eligible Aboriginal families were not informed, and subsequently did not access, government travel support initiatives. Concerns regarding eligibility, application processes and the restrictive nature of these schemes on Aboriginal patients, has been reported for cancer treatment [393, 394] and more generally in the Northern Territory [395]. Reasons for not informing patients include health professionals and administration staff not comprehending the extent of OOPHE or being

unaware of government funded travel support schemes [395]. ALO or AHW, play a pivotal role in advocating for patients and are in a prime position to provide links to transport and social support programs. Mandatory referral for Aboriginal patients and their families to an AHW/ALO would assist in navigating and accessing support initiatives [351].

Our study identified injury-specific OOPHE described by participants. At home, OOPHE spending on over-the-counter medications and treatment consumables, which were not subsidised for burns patients but important for treatment, were reported [156]. Housing utility bills also increased due to the ongoing cleaning of pressure garments for scar management. Comparable to previous OOPHE research, participants experienced significant stress and anxiety in being able to keep up with household bills and meet their injured child's care needs [392]. In all cases, the child's health was a priority but this often came at an expense to families; paying bills late, selling of personal items, accessing savings, reaching credit card limits or asking family for help. While these actions were a first response to prevent further financial burden, they also indicated financial stress [156, 164]. If OOPHE are prolonged or intensified, where all protections have been exhausted, catastrophic healthcare expenditure can be induced, which can push families into poverty [156]. Additionally, for Aboriginal parents, increased financial stress negatively impacts parenting efficacy; decreased parenting efficacy and economic hardship consequently impacts on a child's recovery from injury [10, 103, 312].

Strengths and Limitations

Led by Aboriginal researchers and using decolonising methodology, this work has produced rich contextual data. Findings from this study have been used to modify and psychometrically assess OOPHE for Aboriginal families. Limitations in this study include the small sample size and focus on acute burns only.

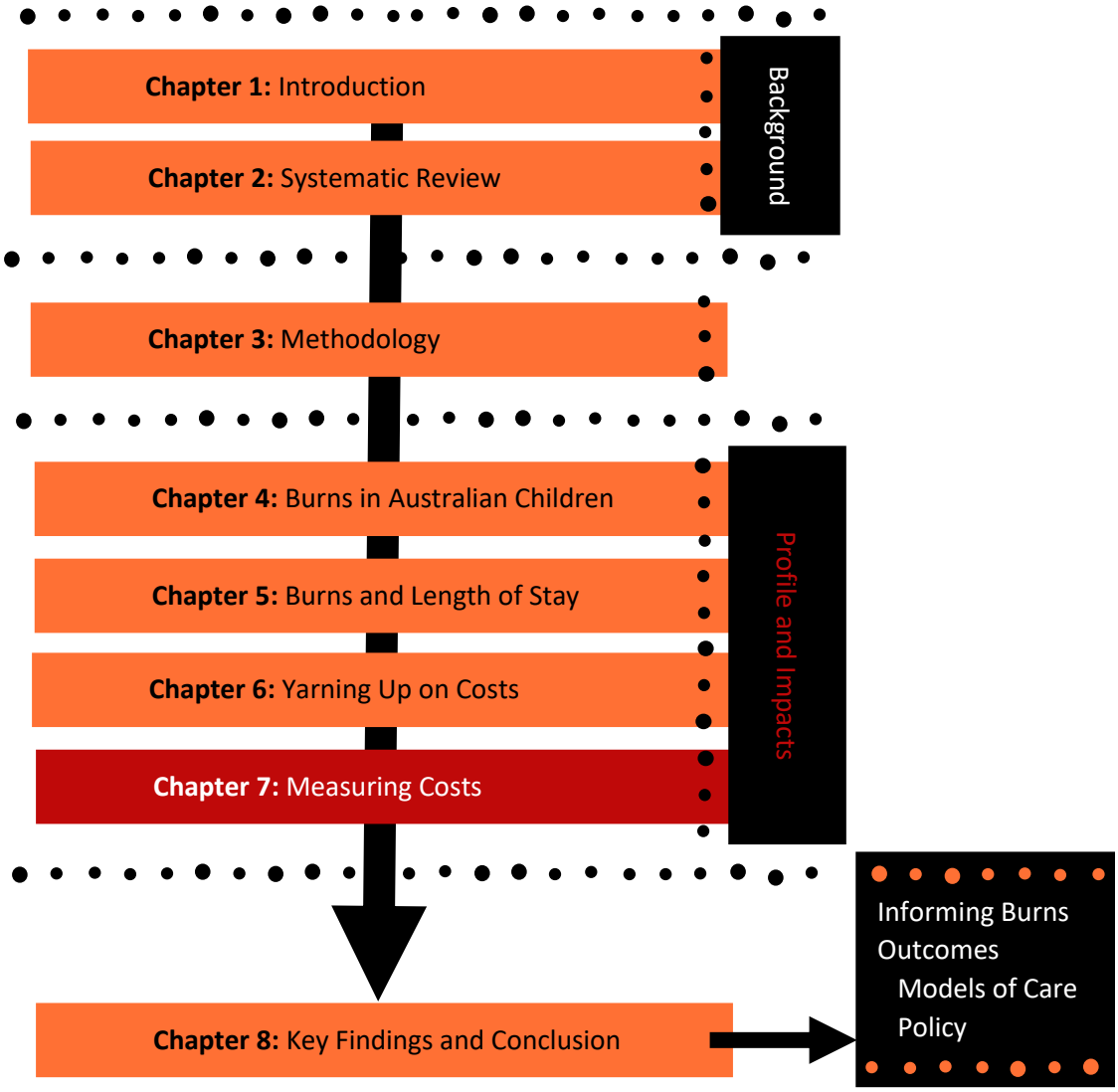
6.7 Conclusion

Aboriginal families whose child has sustained a severe burns injury are impacted financially through OOPHE for their child's initial and ongoing treatment, especially those residing rurally or with reduced employment capacity. Aboriginal family connections and networks were mitigating factors for OOPHE and critical in decreasing financial stress. Our results highlight the need to contextualise the assessment of OOPHE, such as injury area or disease as there are condition-specific costs borne by families. Future studies in this area need to consider OOPHE

across a range of conditions, as well as the specific cultural and social nuances for Aboriginal families when developing OOPHE tools for Aboriginal communities.

CHAPTER 7

Measuring Costs - Assessment of an Out-of-Pocket Healthcare Expenditure Tool for Aboriginal and Torres Strait Islander Families



7.1 Preamble

Aboriginal and Torres Strait Islander children have a greater burns incidence than other Australian children and experience extended hospital LOS for their burns injuries, as demonstrated in Chapters 4 and 5. Extended hospital LOS and the ongoing treatment and follow-up required for acute burns injuries creates additional burden on Aboriginal and Torres Strait Islander families through OOPHE. Scoping OOPHE with Aboriginal families whose child had sustained an acute burns injury identified a range of themes in Chapter 6. This chapter builds on the work presented in Chapters 4, 5 and 6 through the modification of an existing OOPHE for use with Aboriginal and Torres Strait Islander families. The outcomes from this study informed recommendations in Chapter 8.

A special thank you to the following organisations who assisted with the recruitment in this study: HealthInfonet, Indigenous Allied Health Association, Australian Indigenous Doctors Association, Leaders in Indigenous Medical Education, Aboriginal Health Council of South Australia, Centre of Research Excellence - Research Excellence in Aboriginal Child and Adolescent Health and Engineering Aid.

This chapter is under review with the Australian Health Review:
Ryder, C., Mackean, T., Coombs, J., Hunter, K., Ullah, S., Rogers, K., Essue, B., Holland A.J.A., and Ivers, R., Developing Economic Measures for Aboriginal and Torres Strait Islander Families on Out-of-Pocket Healthcare Expenditure.

Corresponding Author: Courtney Ryder

7.1.1 Summary: Weaving the Interface

> *"In changing the 'who' of who has the power to make the assumptive determinations that shape data practices, the terrain of what is the problematic, what needs to be measured, how it is measured and very often who is doing the measuring is also changed".*
>
> Maggie Walter [330(p.116)]

Weaving the methodology for 'research at the interface' for this chapter was different to the previously outlined work in Chapters 4 and 5. The knowledge interface for the research in this

chapter was focussed on psychometric and decolonising methodologies, as illustrated in Figure 16.

In this woven knowledge interface there are five main sections (Figure 16). As in prior chapters, the strands and intersectional points will be described further to provide readers with an appreciation of the Indigenous and Western knowledge systems.

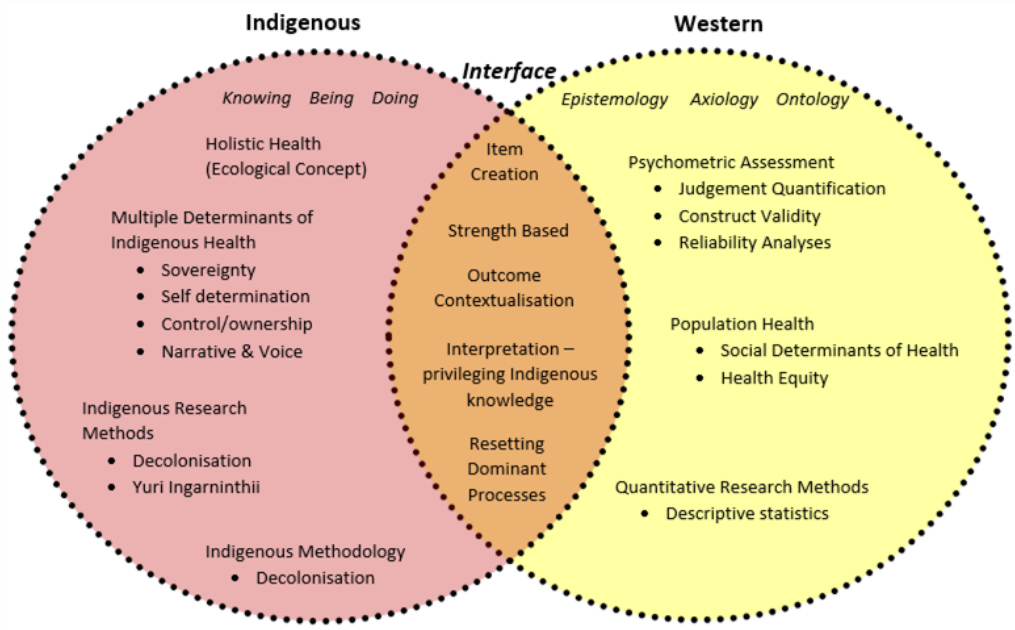


Figure 16: Visual representation for research at this knowledge interface.

Item Creation

The selected OOPHE survey was developed from a Western biomedical standpoint of health and illness. Decolonising research methods were employed to redesign items from this survey specifically for Aboriginal and Torres Strait Islander families. Indigenous Knowledge focussed on OOPHE (from the scoping study in Chapter 6), concepts of holistic health and the multiple determinants of Indigenous health were employed for this process. This was an important part of the decolonising methodology, as Western epistemology and knowledge in this area has not focussed on Indigenous Knowledges[285]. Additionally, Yuri Ingarninthii was important for item creation through ensuring that the central themes from the knowledge and narrative that had been provided by participants in Chapter 6 was used to transform items. In this process, a decolonising approach was used, where items from the Essue survey were explored in terms of their Western dominant assumptions, beliefs and structuring [285]. These items were then

remoulded to incorporate key ideas and themes, central to Aboriginal world views, understanding and lived experience of OOPHE. On completion of the OOPHE survey, each item was reviewed by a panel of experts with specific expertise and knowledge in the area of Aboriginal health, OOPHE and injury.

Strength Based

Engagement with decolonising methodology was important for the overall study design and outcomes of this research; employing Indigenous research methods in this woven interface ensured a strength based approach focussed on Indigenous Knowledge was undertaken. Psychometric assessment of quantitative measures is firmly embedded in a Western knowledge system (i.e. quantitative research methods of validity or reliability). This is not to dismiss the imperative process of psychometric assessment, but to ensure decolonisation is employed to leverage and critically analyse these processes and understand whether they were enabling, assumptive or disempowering. Drawing on critically relevant Indigenous Data Sovereignty scholarship and Indigenous Knowledge ensured outcome contextulisation where needed. This was further shaped by the experience of Ryder, her Aboriginal supervisor and other Aboriginal chief investigators over the journey of the Coolamon study. For example, regarding the contextualisation of systematic differences in the OOPHE outcomes most pilot studies are undertaken in dominant populations - are these outcomes relevant and of use to psychometric assessment in Aboriginal and Torres Strait Islander health research?

Outcome Contextualisation

The majority of research surrounding psychometric assessments comes from a Western knowledge of quantitative research methods (validity, reliability). These are processes which were imperative to the psychometric assessment of this sturvey and could not be undertaken without them. However, to ensure that outcomes were contextualised, Ryder participated in Yarning with two senior biostatisticians and her Aboriginal supervisor. Yarning was conducted either face to face or over the phone and occurred multiple times throughout the study. This process ensured that knowledge from both world views was brought together in the knowledge interface of this study, specifically for contextualisation purposes. Ryder also drew on critical and relevant Aboriginal scholars in this area, Professor Maggie Walters and Professor Kukatai. Their ground-breaking work in Indigenous Data Sovereignty and Indigenous quantitative research was imperative in contextualising the outcomes of this psychometric assessment.

Interpretation – Privileging Indigenous Perspectives and Voice

Western knowledge systems are the area of focus in psychometric assessment, which draws on biostatistical concepts, epidemiology and public health. While these knowledge systems were important to the knowledge interface of this study, it was not defined by it. In this study, Indigenous perspectives and voice were privileged, as outlined in the headings above, and as described in other chapters. In addition to this and where possible, core Indigenous Knowledge in outcome contextualisation were drawn from First Nations scholars, for example:

- Kite (2015), in using Indigensit and Indigenous Knowledges in the creation of quality of life measures [396]
- Kukutai (2016), the importance of decolonisation in an agenda towards Indigenous data sovereignty [330]
- Walter (2019), the importance of gold standard approaches which engage Indigenous Knowledges and research methodologies in quantitative research [145].

Resetting Dominant Processes

Western quantitative research, with a focus on psychometric assessment, is embedded firmly in normative colonial frameworks and hold invisible and unacknowledged privilege and power for the dominant population. This study was about resetting normal dominant processes through the modification of an OOPHE survey specifically for use with Aboriginal and Torres Strait Islander communities. All the principles outlined above were about resetting this dominant narrative.

Additionally, for the psychometric assessment process we worked with a range of critical Aboriginal and Torres Strait Islander organisations that work in this space: HealthInfonet, Indigenous Allied Health Association, Australian Indigenous Doctors Association, Leaders in Indigenous Medical Education, Aboriginal Health Council of South Australia, Centre of Research Excellence - Research Excellence in Aboriginal Child and Adolescent Health and Engineering Aid. These organisations happily came on board to assist in participant recruitment for this survey via social media or email. This assisted in ensuring that only Aboriginal and/or Torres Strait Islander families were approached and participated in this study.

ARE WE AT THE INTERFACE?

There are four important principles that determine if research is at the interface.

Mutual Respect

Throughout this study, both knowledge systems were important and valid in achieving the outcomes of this study. Ryder acted to allow both systems to complement each other throughout this process and not allow dominant normative frameworks and knowledge to underpin this study.

Shared Benefits

The benefits for Western knowledge are evident in the outcomes of this study. These outcomes also provide added strength to Indigenous Knowledge and voice in the area of quantitative statistics, particularly psychometrics, and the development of quantitative measures. This research adds to the agenda of Indigenous data sovereignty.

Human Dignity

Human dignity was the essence of this study, through the decolonisation of an OOPHE survey specifically for Aboriginal and Torres Strait Islander communities. While the outcomes of this study are not the quintessentially ideal outcomes, what this research has provided is additional knowledge and understanding of the importance of human dignity and Indigenous Knowledges. Generic quantitative measures, designed and tested on dominant cultural populations, are not suitable or appropriate for Aboriginal and Torres Strait Islander communities. Human dignity ensures that Indigenous Knowledges are central and these measures must ensure that they contain important cultural contextual factors relevant to Aboriginal and Torres Strait Islander communities.

Discovery

New knowledge has been discovered in this knowledge interface. This new knowledge is different and challenging in nature as it questions the relevance and use of Western-constructed quantitative measures in the space of Aboriginal and Torres Strait Islander health. It suggests that there are important cultural and contextual factors which are missing and that future quantitative measures (surveys and questionnaires) should be developed from the outset with Aboriginal and Torres Strait Islander families.

7.2 Abstract

Background: OOPHE impacts significantly on marginalised households. The purpose of this study was to modify a pre-existing OOPHE survey for Aboriginal and Torres Strait Islander households with children.

Methods: The OOPHE survey was derived through a scoping review and face and content validity, including judgement quantification with content experts. Exploratory factor analyses determined factor numbers for construct validity. Repeatability through test-retest processes and internal consistency was assessed to examine reliability.

Results: The OOPHE survey had 168 items and was piloted on 67 Aboriginal and Torres Strait Islander parents. Construct validity assessment generated a 62-item correlation matrix with a 3-factor model. Across these factors items loadings varied; ten items with high correlations (0.70<) and twenty with low correlations (<0.40). An OOPHE survey retest was conducted with 47 families, where 43 items reached slight to fair levels of agreement.

Conclusion: The low level of item loadings to Factors in the OOPHE survey indicates interconnectedness across the 3-factor model and reliability results suggest systemic differences. These may be unrelated to the survey but cohort homogeneity and survey length could be impeding factors. It is unknown how cultural and social nuances specific to Aboriginal and Torres Strait Islander households impacts on results. Further work is warranted**.**

7.3 Introduction

> *"Our services are tired of seeing patients go without medicines and get really ill because they physically can't get to a chemist shop, or because they can't afford their medicines".*
>
> Dr Puggy Hunter as cited in Murray [397(p. 106)]

Out-of-pocket healthcare expenditure is a global health concern, significantly impacting families and patients who experience the greatest health inequities [155-161]. OOPHE are any expenses not covered through universal taxpayer-funded health insurance or private health insurances and relate to the illness or condition. In high income countries, OOPHE is enabled through increasing reliance on healthcare co-payments by patients and the expectation of patients to fund other healthcare needs. This includes transportation to access health-related appointments and additional pharmaceutical costs, or equipment purchase. In addition to OOPHE patients and families also face indirect costs related to loss of income from being sick or caring for family members who are sick.

In Australia, the health service is structured as a taxpayer-funded health insurance known as Medicare [155, 164]. Medicare includes the Medical Benefits Scheme and Pharmaceutical Benefits Scheme, which are applied across a range of healthcare settings [164]. Households can purchase private health insurance for coverage at private hospitals and subsidies of other services. This does not protect all Australians, with households reporting lower confidence in affording healthcare for serious illness when compared to households in other high-income countries, such as United Kingdom, New Zealand and Sweden [398]. The impact that OOPHE has on Australian households includes sacrificing general necessities (food, clothing and accommodation), medication compliance from inability to afford prescriptions, delaying or not seeking medical treatment, through to significant economic hardship which induces bankruptcy [155, 156, 161, 162, 379-381].

In Australia, the majority of OOPHE research has focussed on the general population, or on older people suffering from chronic conditions [156-158]. There is limited research exploring the substantial burden, financial hardship or specific cultural and social nuances of OOPHE on Aboriginal and Torres Strait Islander families. This is despite Aboriginal and Torres Strait Islander patients having a higher burden of chronic disease; reporting their health as poorer; higher admissions to tertiary health services, and a greater risk of economic hardship due to the management of chronic conditions, such as chronic heart failure, as compared to other Australians [8, 168]. In Australia, Aboriginal and Torres Strait Islander children have a higher burden of burns injury compared to other Australian children. The Coolamon study is a large study exploring this impact, including the financial implications of burns injury for Aboriginal and Torres Strait Islander families [75]. In this study, OOPHE explorative work has been conducted with Aboriginal families, revealing the OOPHE impacts and financial strain on households (Chapter 6).

The aim of this study was to modify an existing Australian OOPHE survey and psychometrically assess this survey for Aboriginal and Torres Strait Islander households. It is commonplace in the current health and medical research setting to use survey tools which are only psychometrically assessed in the dominant Australian population. This is not optimal for Aboriginal and Torres Strait Islander communities as it reinforces dominant colonial knowledge constructs [396, 399]. To address this gap, this study aimed to:

1. Conduct a scoping review of OOPHE measures for Australian households

2. Assess a modified version of an OOPHE measure with Aboriginal and Torres Strait Islander households.

7.4 Methods

Knowledge interface methodology was employed in this study, bringing together psychometric assessment survey methods (Figure 17) with Indigenous Knowledges (Figure 16)[1, 261]. Indigenous Knowledges were important for the overall study conceptualisation (item creation, participant focus, outcome contextualisation, interpretation and resetting dominant norms). In this process, the first author drew on their own lived experience as an Aboriginal woman, decolonisation methodologies, Indigenous data sovereignty processes and Yarning with their Aboriginal supervisor and members of the Coolamon Study Aboriginal Steering Committee [2, 144, 330]. This approach was important in ensuring an appreciation of both knowledge systems, one where the required psychometric assessment methods for the OOPHE survey could be conducted, but enquired and informed upon, in the context of Indigenous Knowledges.

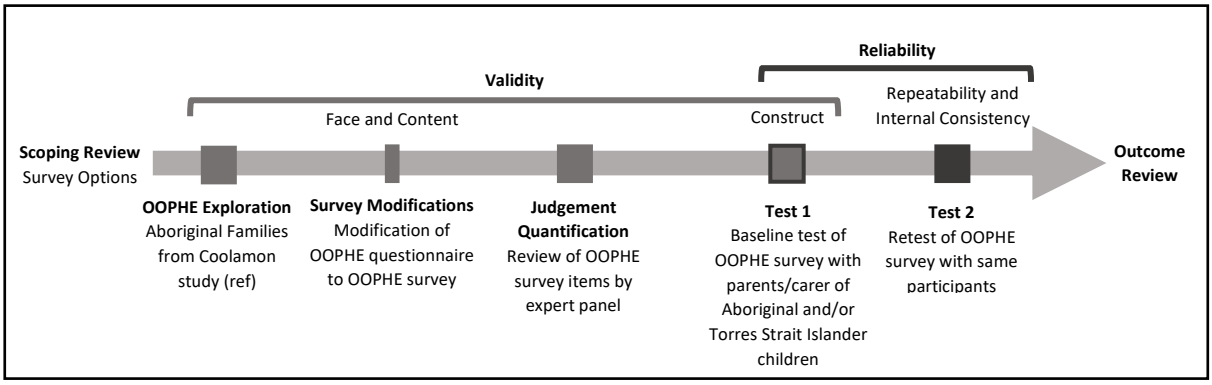


Figure 17: Process of psychometric assessment undertaken for modification of the OOPHE questionnaire.

Scoping Review

A scoping review was conducted in May 2017 to identify OOPHE tools specific to Australian households, following methods outlined by Munn *et al* [400]. Four key databases were searched (Medline, Scopus, web of science, and Google scholar), using a combination of key search terms of "out-of-pocket" and "Australian", in the title or abstract. A total of ten papers met inclusion requirements: studies on OOPHE focussed on Australian patients/carers/families/households over the last ten years. Various methods (interviews, surveys, mixed and general estimations) were used in these studies to determine OOPHE impacts on Australian households, with the majority (80%) using surveys. In these eight studies, four different OOPHE surveys featured:

- Financial stress scale [401]
- OOPHE questionnaire [156]
- Economic Survey [402]
- Questionnaire (no details) [403].

No psychometric assessment had been conducted on any of these surveys. The OOPHE questionnaire was used in 40% of the studies making it the most commonly used survey [156, 160, 164, 404]. Although psychometric assessment had not been conducted on the OOPHE questionnaire, it was selected as being the most appropriate for modification as it contained focussed and targeted items on OOPHE.

Validity - Face and Content

Judgement Quantification

Judgement quantification for face and content validity, with content experts, followed similar processes to Ryder et al (2017) and Lynn (1986)[138, 302]. The content experts consisted of five professionals:

- a burns specialist with clinical experience in remote and Aboriginal health settings in the Northern Territory
- health economist specialised in OOPHE measures in Australia
- Aboriginal health researcher specialised in chronic conditions
- Two injury researchers specialised in housing, injury and women's health and Aboriginal and Torres Strait Islander Health.

Each was contacted directly to participate through the lead author (Appendix D, D.1 Invitation). Content validity index (CVI) was used for assessment where content experts rated the relevance of each item in the OOPHE survey on a 4-point Likert scale to determine item-level CVI (I-CVI))(Appendix D, D.2 Instructions) [301, 302]. I-CVI was calculated from content expert responses; items in the OOPHE survey with I-CVI > 0.80 remained unchanged; items with I-CVI of 0.50-0.80 were modified on content expert input and items >0.50 were removed. Inter-rater reliability was calculated through interclass correlation coefficient (ICC) through a two-way mixed effects model where ICC values <0.50 indicated poor reliability, 0.50-0.75 moderate reliability, 0.75-0.90 good reliability and values > 0.9 excellent reliability [405-407]. All calculations were completed using Stata version 15.1 (StataCorp).

Validity and Reliability

Participants

Participants for this study were parents/carers of Aboriginal and Torres Strait Islander children. Participants were included in the study if they identified as an Aboriginal and/or Torres Strait Islander family, where one parent/carer in this family identified as an Aboriginal and/or Torres Strait Islander person, their children were under the age of 16 years, the parent/carer had internet and accessed social media and sales platforms (i.e. Facebook or Gumtree) and email. A target sample size of 30 participants was established for OOPHE survey assessment: this target size is recommended for pilot studies and has been used in other studies testing surveys for psychometric assessment [408-411]. The OOPHE survey was administered through REDCaps, where participants were reminded via email and/or text message to complete the survey at the two-week interval period.

Validity - Construct

Exploratory factor analysis (EFA) was used to discover the number of distinct factors (latent constructs) and examine the pattern of inter-relatability between items in the OOPHE survey [304, 305]. Data were cleaned and reviewed prior; this review only required the inclusion of OOPHE survey items specific to capturing OOPHE, as well as items which met polychloric correlation assumptions. OOPHE survey items were then constructed into a polychloric correlation matrix for continuous, ordinal and binary items. EFA suitability was examined for common variance through a Kaiser-Meyer-Olkin (KMO) measure of sampling where a value > 0.5 was considered suitable and equal variance through Bartlett's Test of Sphericity, where a p-value < 0.05 was considered appropriate [138, 412, 413]. Scree plots and parallel analyses were used to determine the number of factors to retain and promax rotation was used to simplify the factor loading matrix structure for EFA and data interpretation [304, 414, 415]. Internal reliability was calculated by Cronbach's alpha on factor discovery; high values are desirable - we decided values >0.70 were considered good and values of 0.50-0.70 were adequate [138, 416, 417]. For items which did not have a clear and concise loading, or were cross-loaded to factors, a value of 0.15 was considered the lowest acceptable cut-off for loading [418].

Reliability – Repeatability and Internal Consistency

Reproducibility of the OOPHE survey using test-retest methods over an interval of two weeks was used to assess reproducibility and item internal consistency. A two-week interval period was deemed a suitable period for this assessment and to decrease the impacts of response

shift by participants; this time frame has also been used in previous studies [138, 303, 308, 419-421]. ICC one-way random effects model was used for continuous items; weighted kappa for polytomous items with quadratic weighting for items with ordinal scales and kappa for dichotomous items to assess reliability [307, 308, 405-407]. Where outputs of 1.00-0.81 represented perfect agreement, 0.80-0.61 substantial agreement, 0.60-0.41 moderate agreement, 0.40-0.21 fair agreement, 0.20-0.00 slight agreement and < 0.00 poor agreement, based on the scale from Landis and Koch [422]. Internal consistency of each item scale was calculated using Cronbach's Alpha, where an α score of ≤0 demonstrates no agreement, ≤0.5 unacceptable agreement and ≥0.7 acceptable agreement [306]. All calculations were conducted in Stata version 15.1 (StataCorp).

Ethics

Ethics approval was acquired from the following jurisdictions (Table 25):

Human Research Ethics Committee	State
Aboriginal Health and Medical Research Council	NSW
Sydney Children's Hospitals Network Human Research Ethics Committee	NSW
Townsville Hospital and Health Service Human Research Ethics Committee	QLD
Children's Health Queensland Hospital and Health Service Human Research Ethics Committee	QLD
Human Research Ethics Committee Office of Research Ethics the University of Queensland	QLD
Aboriginal Health Research Ethics Committee	SA
Women's and Children's Health Network Human Research Ethics Committee	SA
Flinders University Human Research Ethics Committee	SA
Central Australian Human Research Ethics Committee	NT
Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research	NT

Table 25: Human Research Ethics Approval for Pilot Study by Jurisdiction.

7.5 Results

Validity – Judgement Quantification

A total of 4 out of 5 expert panel members participated in the survey content review. ICC inter-rater reliability between individual items was calculated at 0.23 (indicating poor reliability) but the absolute ICC was calculated at 0.55 indicating moderate reliability [405]. From the I-CVI on the modified Essue OOPHE questionnaire which originally contained 192 items, 25 items were removed, 33 items modified and one item added, based on feedback from content experts. This led to the final iteration of the OOPHE survey that was piloted, containing 168 items.

Pilot Study - Participant Demographics

A total of 67 parents participated in Test 1 of the OOPHE survey, where 47 parents went on to complete Test 2. Most parents who participated were male, between the ages of 34 – 44 years

of age and identified as Aboriginal and Torres Strait Islander and were employed (Table 26). Most households were in metropolitan locations and reported middle socio-economic status.

Demographic Variable	N	%	Demographic Variable	N	%
Age Range			**Cultural Status of Child(ren)**		
25 – 34 Years	16	23.9	All are Aboriginal	63	94.0
35 – 44 Years	48	71.6	Some are Aboriginal	3	4.5
45 – 54 Years	3	4.5	**Child Stayed Overnight in Hospital**	63	94.0
Gender**			Parent Currently Employed	58	86.6
Female	32	47.8	**Residential Location***		
Male	35	52.2	Metropolitan	40	59.7
Cultural Status			Inner & Outer Regional	25	37.3
Aboriginal & Torres Strait Islander	30	44.8	Remote & Very Remote	2	3.0
Aboriginal	25	37.3	**Socio-Economic Status***		
Torres Strait Islander	10	14.9	High (8 to 10)	17	25.4
Other Australian	3	3.0	Middle (4 to 7)	29	43.3
Children at Home			Low (1 to 3)	20	29.9
1 Child	39	58.2	* Residential Location and Socio-Economic Status derived from SEIFA and ARIA from the Australian Bureau of Statistics ** No reported indeterminant or gender neutral		
2 or 3 Children	26	38.8			
4 or More Children	2	3.0			

Table 26: Parent Demographics from Test 1 (n = 67)

Validity - Construct

Cleaning and review of Test 1 for the OOPHE survey (Appendix D, D.4 Refinement Diagram) resulted in construction of a 62-item correlation matrix for EFA. Suitability for EFA provided a KMO value of 0.00 (undesirable) and Bartlett's Test of Sphericity p<0.00 (appropriate). Scree Plot (Figure 18) and parallel analyses with the application of the Kaiser's criteria (eigenvalues > 1.0) suggested a 3 factor model for the OOPHE survey [305, 423].

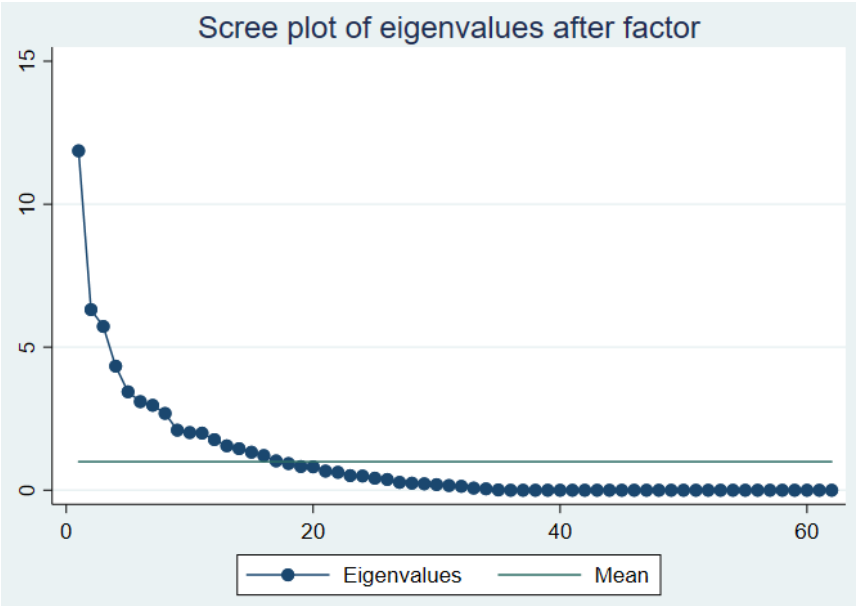


Figure 18: Scree Plot of eigenvalues after EFA

Over half of the items (n= 34) loaded to Factor 1, which on item review was named Financial Strain/Impacts (Table 27). Factor 1 ranged from 0.21 to 0.81, with 32% (n=11) of items loaded with low correlations (< 0.40), and 12% (n=4) loaded with high correlations (> 0.70). Similar was found in Factor 2 (Family Income & Support) with 33% (n=5) loading with low correlations (0.15-0.39) and Factor 3 (Injury/Condition Impacts) with 40% (n=4) loading with low correlations (0.22-0.40). Over half of the items (60%, n = 6) did load with high correlations (0.70-0.90) to Factor 3, whereas only 13% (n=2) loaded with high correlations (0.70-0.75) to Factor 2.

Factor 1 (items = 34)			**Factor 2 (Items = 15)**			**Factor 3 (Items = 10)**		
Financial Strain/ Impacts	Alpha	0.71	*Family Income & Support*	Alpha	0.46	*Injury/Condition Impacts*	Alpha	0.38
	Deleted*	0.83		Deleted*	0.63		Deleted*	0.55
Items	Loading		Items	Loading		Items	Loading	
Injury11	0.44		Injury27	0.52		Injury3	0.40	
TreatmentSupport3	0.39		Injury30	0.66		Followup1	0.90	
TreatmentSupport6	0.21		Injury 34	0.42		Followup2	0.81	
Government1	0.24		Government7	0.31		Followup15	0.38	
Government4	0.32		TreatmentSupport1	0.51		Followup16	0.84	
Finances2	0.43		TreatmentSupport2	0.53		Followup17	0.83	
Finances3	0.54		TreatmentSupport4	0.61		Outpatients1	0.76	
Finances4	0.49		TreatmentSupport5	0.75		Outpatients2	0.83	
Finances5	0.51		TreatmentSupport7	0.54		Government3	0.47	
Finances9	0.52		TreatmentSupport8	0.70		Finances14	0.22	
Finances10	0.59		Financial1	0.44				
Finances12	0.68		Finances1	0.39				
Finances13	0.69		Finances8	0.34				
Finances15	0.49		Finances11	0.15				
Finances16	0.60		Finances43	0.36				
Finances18	0.46							
Finances20	0.58							
Finances21	0.38							
Finances22	0.74							
Finances24	0.64							
Finances25	0.75							
Finances26	0.67							
Finances27	0.38							
Finances28	0.56							
Finances30	0.37							
Finances31	0.71							
Finances32	0.50							
Finances33	0.24							
Finances34	0.66							
Finances35	0.53							
Finances36	0.40							
Finances37	0.21							
Finances38	0.31							
Finances39	0.81							
Items - Injury33, Finances44, and Finances47, did not meet loading cut-offs (≥ 0.15). * Cronbach's alpha if deleted.								

Table 27: Exploratory Factor Analyses and Internal Consistency of OOPHE survey (n=67, Items = 62)

Reliability – Repeatability and Internal Consistency

Test-retest reliability results (Table 28) indicated that 75% of OOPHE survey items (n=43) reached slight to fair agreement, with an ICC range from 0.03-0.22 for continuous items, and 0.00-0.60 Kappa range for ordinal and binary items. The remaining 14 items reached a poor level of agreement with ICC and Kappa ranges below 0.00. Internal reliability reached a good level (> 0.70) for Factor 1 - Financial Strain/Impacts at 0.71 and inadequate for Factor 2 – Family Income and Support at 0.46 and Factor 3 – Injury/Condition Impacts at 0.38 (Table 26). The internal consistency for all items reached a good level (0.72), factor removal improved internal consistency to 0.83 for removal of Factor 1 but did not improve for removal of Factor 2 (0.63) or Factor 3 (0.55).

Item	Agreement	ICC/Kappa (CI)	Item	Agreement	ICC/Kappa (CI)
Injury 3		0.22 (-0.08-0.48)	Finances8	53.3%	-0.26 (-0.44- -0.06)
Injury11	72.2%	-0.18(-0.24-0.23)	Finances9	70.65%	0.01 (-0.19-0.31)
Injury27	50.0%	0.00 (0.00–0.00)	Finances10	82.6%	0.12 (-0.2-0.46)
Injury30	76.1%	0.51 (0.28-0.74)	Finances11	56.52%	0.15 (-0.12-047)
Injury33	88.6%	0.28 (-0.07-0.55)	Finances12	80.43%	0.12 (-0.14 - 0.47)
Injury 34	91.58%	-0.28 (-0.56-0.06)	Finances13	89.96%	0.50 (0.17 - 0.84)
FollowUp1	68.12%	0.00 (-0.21-0.22)	Finances14	63.04%	0.27 (0.01 - 0.53)
FollowUp2		0.2 (-0.09-0.46)	Finances15	86.96%	0.33 (-0.08 - 0.74)
FollowUp15		0.03 (-0.26-0.31)	Finances16	80.43%	0.10 (-0.22 - 0.41)
FollowUp16		-0.03 (-0.32-0.26)	Finances18	78.26%	0.18 (-0.13 - 0.50)
FollowUp17		-0.01 (-0.27-0.27)	Finances20	76.09%	0.05 (-0.27 - 0.36)
Outpatients1		0.40 (0.13-0.62)	Finances21	76.09%	0.18 (-0.04 - 0.47)
Outpatients2		0.20 (-0.08 – 0.45)	Finances22	66.30%	0.03 (-0.19 - 0.28)
TreatmentSupport1	74.5%	0.00 (-0.19-0.22)	Finances24	89.13%	0.56 (0.24 - 0.89)
TreatmentSupport2	79.9%	0.04 (-0.12-0.19)	Finances25	76.09%	0.28 (-0.03 - 0.60)
TreatmentSupport3	56.5%	-0.12 (-0.29-0.09)	Finances26	78.26%	0.16 (-0.18 - 0.50)
TreatmentSupport4	76.8%	0.24 (0.03-0.44)	Finances27	65.22%	0.00 (-0.27 - 0.27)
TreatmentSupport5	82.6%	0.26 (0.08 – 0.49)	Finances28	89.13%	0.60 (0.29 - 0.92)
TreatmentSupport6	83.2%	0.03 (-0.15-0.26)	Finances30	65.22%	0.21 (-0.08 - 0.50)
TreatmentSUpport7	77.2%	0.05 (-0.16-0.24)	Finances31	56.52%	-0.01 (-0.21 - 0.20)
TreatmentSupport8	72.3%	-0.1 (-0.27-0.07)	Finances32	65.22%	0.07 (-0.15 - 0.29)
Government1	75.0%	0.12 (-0.13-0.41)	Finances33	52.17%	-0.04 (-0.13 - 0.04)
Government3	48.6%	0.01 (-0.20-0.19)	Finances35	67.39%	0.16 (-0.13 - 0.44)
Government4	68.5%	-0.16 (-0.39-0.09)	Finances36	60.87%	-0.21 (-0.37 - -0.05)
Government7	81.5%	0.05 (-0.05-0.27)	Finances37	50.00%	0.04 (-0.04 - 0.12)
Financial1	83.2%	0.19 (-0.01-0.47)	Finances38	50.00%	-0.1 (-0.38 - 0.17)
Finances1	79.7%	-0.01 (-0.18-0.19)	Finances39	56.52%	0.12 (-0.15 - 0.39)
Finances2	89.1%	0.39 (-0.03-0.81)	Finances43		0.05 (-0.14-0.27)
Finances3	84.8%	0.19 (-0.13-0.52)	Finances44	62.32%	-0.08 (-0.24 - 0.07)
Finances4	78.26%	0.16 (-0.13-0.49)	Finances47	74.64%	0.16 (-0.03 - 0.35)
Finances5	81.5%	0.21 (-0.06-0.55)			

Table 28: Test retest reliability of OOPHE survey (n=47)

7.6 Discussion

In this study, we modified an existing OOPHE survey, using face and content validity and psychometric pilot testing. Construct validity identified a 3-factor model through EFA. Around 20% of items (n=12) produced high loadings, representing good interconnectedness with their factors [305]. Although 32% (n=20) of items produced low correlations with their factors, the remaining 48% (n=40) of items produced medium level (0.4-0.7) loadings: this suggests

interrelatedness between factors which transpires through factor cross loadings [305, 424]. Given this is the first iteration of the OOPHE survey for Aboriginal and Torres Strait Islander households, it is likely that items are not measuring one concise latent construct, but in actual fact items are exhibiting interconnectedness across the 3-factor model [424, 425].

The majority of OOPHE survey items met a reliability level of slight to fair agreement (75%, n=43). For the 14 items which yielded a poor level of reliability, half (n=7) loaded to Factor 1 and a third (n=5) related to Factor 2. In addition, most of these items (n=8) had an ordinal response scale. The poor kappa produced in these items could be due to chance but are more likely caused from systemic differences. These systematic differences could be due to factors unrelated to the OOPHE survey, such as the homogeneity of the parent cohort (Table 26). In our cohort, most parents where employed, aged 35 - 44 years, with only one child at home. Homogeneity in study cohorts, has been found to decrease reliability estimates of surveys [419, 426]. High study attrition can also contribute, in our study we had a 30% attrition rate between test 1 and test 2, this can create a situation where the test 2 homogeneity is greater than test 1, further impacting reliability measures [419]. Additional systemic differences impacting on item reliability have been suggested in dominant populations, such as: parent rehearsal or recall where parent reflection alters item responses the second time, and transition errors where variations in mood or feelings from parents impacts on item responses for the retest [419]. These systematic differences could be related to item and scale clarity, expression and interconnectedness, along with the overall length and time needed to complete the OOPHE survey [138, 416, 425]. Poor reliability results have also been associated with surveys which take longer periods of time to complete: this would be especially true for parents whom are time poor or mentally fatigued form full time work, children's extracurricular activities, managing households or additional extended family obligations [427]. A range of these systematic differences may not be applicable in this context, as they are grounded in concepts and understandings from the unacknowledged but dominant population [330]. It is unclear how impacts of marginalisation from ongoing colonisation, transgenerational trauma and grief, holistic concepts of health and well-being, culturally unsafe settings and the multiple determinants of Indigenous health, manifest in this area as they remain unexplored, but are important for First Nations households and must be considered in future work.
This pilot study has demonstrated pertinent points for future work in this area, such as the complexities in developing robust, culturally safe and specific surveys, which reach ideal

psychometric levels of validity and reliability for Aboriginal and Torres Strait Islander communities. Certainly, it is our recommendation that in the absence of purpose-built surveys generic surveys must be adapted for use with Aboriginal and Torres Strait Islander communities. This requires a gold standard approach to psychometric assessment, which further engages with Indigenous knowledges, research methodologies and methods [145, 330, 396]. Such processes are decolonising in their actions, and act to create data sovereignty in this space for Aboriginal and Torres Strait Islander households [145, 330]. Recommendations for future work in this area, would be to move back to face and content validity. In doing this, researchers must work closely with Aboriginal and Torres Strait Islander families to obtain an understanding of: the unique nature and context of OOPHE on households, appropriate number of items, suitable survey length, ideal scales and measures including the use of visual representations. These factors will ensure the construction of a robust and relevant OOPHE survey for Aboriginal and Torres Strait Islander households. Only after these actions occur can additional psychometric assessment be undertaken with a larger diverse cohort of Aboriginal and Torres Strait Islander households.

Strengths and Limitations

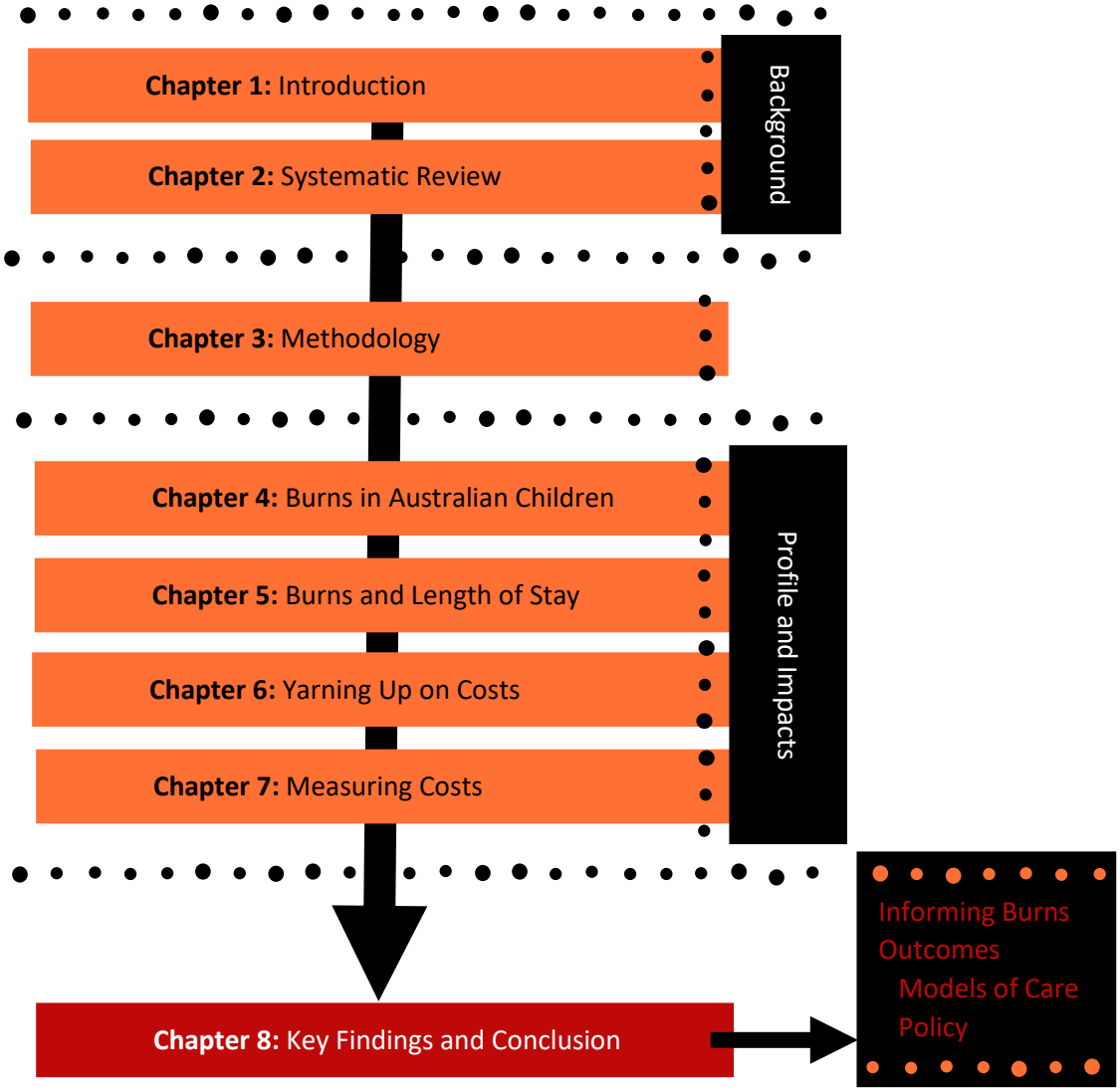
The major strength of this paper was the use of knowledge interface methodology, in which psychometric assessment methods were used with Indigenous research methods, to test a modified OOPHE survey for use with Aboriginal and Torres Strait Islander households. This study faced limitations, KMO assessment did not reach sampling adequacy, the lowest acceptable cut off (0.15) for items which cross-loaded or did not load concisely may have been too low [418]. We continued as this is a pilot study, but note this limitation maybe reflective in our sample to variable ratio [412]. Also, participant bias maybe present through participant homogeneity.

7.7 Conclusion

Aboriginal and Torres Strait Islander families with children who are hospitalised for an injury or condition experience OOPHE impacts. We found that a modified OOPHE survey for Aboriginal and Torres Strait Islander households contained promising items; however, the introduction of contextual factors to a pre-existing survey was impracticable. We recommend that OOPHE surveys should be developed with Aboriginal and Torres Strait Islander families from the outset, so that they can include important contextual factors for Aboriginal and Torres Strait Islander households.

CHAPTER 8

Key Findings, Associations and Conclusions



8.1 Key Findings

> *"'Indigenous Peoples' concept of health and survival is both a collective and individual inter-generational continuum encompassing a holistic perspective incorporating four distinct shared dimensions of life. These dimensions are the spiritual, the intellectual, physical, and emotional. Linking these four fundamental dimensions, health and survival manifests itself on multiple levels where the past, present and future co-exist simultaneously".*
>
> Mason Durie [261(p.1139)]
>
> on Declaration on the Health and Survival of Indigenous Peoples

This thesis is the first body of work to undertake a detailed analyses of health inequity impacts on Aboriginal and Torres Strait Islander children who sustain an acute burns injury. Prior to undertaking this work, it was important to understand how measures of inequity, or health inequities, had been articulated in injury research. A systematic review (Chapter 2) focussed on health inequities and how they are used to describe HRQoL and functional outcomes in children who had sustained an injury. Outcomes from this review suggested that lower SES, hospital LOS, injury severity and poorer family functioning were associated with negative or poorer functional and HRQoL outcomes in children who had sustained an injury. This review identified that current injury research in children is equity blind and contributes to an agenda which reinforces inequity bias. Radical change is needed to reset this approach and ensure that high quality, rigorous equity-focussed research occurs with the community.

The epidemiological profile of acute burns in Australian children demonstrated that the profile for an acute burn causing hospitalisation was different for Aboriginal and Torres Strait Islander children compared to other Australian children (Chapter 4). Burden was greatest in Aboriginal and Torres Strait Islander children with persistent health inequity presence, such as higher proportions of remote residency, lower SES (a manifestation of ongoing colonisation), longer hospital LOS and increased burns severity (full thickness depth, bacterial infection). Furthermore, Aboriginal and Torres Strait Islander children had a much greater risk ratio of *Streptococcus sp.* infection. Reoccurring infections with this species in Aboriginal and Torres Strait Islander children have been linked to glomerulonephritis and kidney disease in later life [346]. Low SES is associated with poorer HRQoL and functional outcomes in injured children [103]. Outer regional to very remote residency indicates equity impacts for access to healthcare services.

Further exploration of hospital LOS revealed that Aboriginal and Torres Strait Islander children on average had a median hospital LOS four days longer than other Australian children (Chapter 5). Prognostic factors contributing to this greater LOS included rural residency (very remote versus metropolitan), primary burns cause (flame versus scald), injury severity (high %TBSA, full thickness burns) and treatment factors (split skin grafts, debridement, allied health intervention). While some of these prognostic factors were identified in other Australian children, differences with greater proportion were apparent in Aboriginal and Torres Strait Islander children, as compared to other Australian children. This serves to highlight the clear health inequities which present in burns injuries and impact on Aboriginal and Torres Strait Islander children and their families. The combination of these health inequities, such as low SES, remote residency and a full thickness flame burn in an Aboriginal child, produces manifestations which create further marginalisation, ie financial hardship from OOPHE or a lack of autonomy through isolation from support networks.

With the findings from Chapters 4 and 5 in mind, clinical teams need to carefully consider the broader impact of burns injuries and health inequities on Aboriginal and Torres Strait Islander children and their families. Prevention and education programs, clinical guidelines, treatment and rehabilitation plans focussed on paediatric burns injuries, together with government policy, needs to reflect the unique and different needs of Aboriginal and Torres Strait Islander children and their families [68, 103, 352, 353]. Such actions act to alleviate burden and decrease the risk of further marginalisation on Aboriginal and Torres Strait Islander families with extended hospital LOS.

This thesis also examined OOPHE in Aboriginal and Torres Strait Islander families as a health inequity manifestation from extended hospital LOS as related to burns injuries. A scoping review of OOPHE tools in Australia revealed that no OOPHE existed specifically for Aboriginal and Torres Strait Islander families; there was a need to develop a specific tool. Scoping of OOPHE with Aboriginal families whose child had sustained an acute burns injury revealed a range of themes (Chapter 6). Costs (ie transport, pain medication, bandages), loss (ie employment capacity, social and community) and support (family, service support) were present as recurring themes. The need to cover OOPHE significantly impacted on families, ranging from restricting social interactions to paying household bills. Close family connections and networks were a protective factor in alleviating financial burden.

The themes from this scoping exercise were used to modify a pre-existing OOPHE tool for Aboriginal and Torres Strait Islander families and conduct a pilot study with psychometric assessment (Chapter 7). This pilot study revealed the complexities in developing robust, culturally safe and specific surveys which reach ideal psychometric levels, for Aboriginal and Torres Strait Islander communities. We found that a modified OOPHE survey for Aboriginal and Torres Strait Islander households contained promising items; however, the introduction of contextual factors to a pre-existing survey was impracticable. Any future work on developing OOPHE surveys must be developed with Aboriginal and Torres Strait Islander families from the outset, so that important contextual factors for Aboriginal and Torres Strait Islander households can be included. Only after these actions occur can additional psychometric assessment be undertaken with a larger diverse cohort of Aboriginal and Torres Strait Islander households.

The last aim of this thesis was to engage with an interface research methodology to combine Western quantitative and public health knowledge, with Indigenous knowledge, for each of the studies. Engaging with this Indigenous research methodology resulted in so much more; the creation of a weaving process, to weave a knowledge interface between Indigenous knowledges and quantitative research knowledge (Chapter 3). Through engaging this process, no system has superiority; rather, both knowledge systems are used to complement and complete each other to answer targeted research questions. There is excitement in this process as it is a safe place, a place for sharing and understanding, a place for innovation and creativity which will only be used for benefit in the future. This allows a rich and vibrant tapestry to be created, akin to a coiled basket, for this research moment in time. This coiled basket aims to specifically hold the research process and outcomes safely and securely in a way to benefit Aboriginal and Torres Strait Islander communities. Each of the studies in this thesis applied this weaving methodology; it is only Chapter 6, as a qualitative study, which focussed on decolonisation methodologies.

8.2 Implications, Recommendations and Future Directions

"…. tired of burying our people. We need to see a dramatic rethinking on the part of politicians and the wider community about Aboriginal health, so that we can get some real changes happening".

Puggy Hunter 1999

as cited in Paul, D [147(p. 236)]

8.2.1. Decolonising Research

"Decolonisation is a method required to shift the current paradigm of Western dominance and colonial amnesia that constructs and maintains Indigenous poor health status".

Juanita Sherwood [372(p. S24)]

Colonisation and imperialism act to suppress the sovereign rights of Aboriginal and Torres Strait Islander communities. Decolonising methodologies and methods act to critically analyse and unpack these processes, in particular, the way that they have motivated, informed or controlled research practices and disciplinary knowledge[288, 311, 372]. In this process, Smith explains that researchers are able to "decolonise our minds, to recover ourselves, to claim a space in which to develop a sense of authentic humanity" [288(p. 24)]. Decolonisation, similar to indigenist and interface methodology, is not about rejecting or refuting Western knowledge; it is about a knowledge equilibrium between that of Indigenous knowledges and Western research knowledge, so that as researchers we can come to understand research and theory but from our world view and for our purposes[83, 131, 146, 174, 234, 235, 246-258, 260-262, 288, 311, 372]. For Aboriginal researchers like me, this act of resistance is an action of our rights, self-determination and sovereignty as First Nations peoples [83, 131, 146, 174, 234, 235, 246-258, 260-262, 288]. Resistance is a way to break free from the knowledge which has created poorly defined deficit discourses, negative enquiries and so-called truths about us as First Nations peoples. Engagement in resistance provides space; it allows research and agendas to be broadened, allows engagement with critical Indigenous knowledges and creates space for new truths and knowledge discovery where meaning and understanding is redefined to encapsulate First Nations sovereign rights [83, 131, 146, 172, 174, 229, 234, 235, 246-258, 260-262, 288].

"Resistance as the emancipatory".

Prof. Lester Irabina Rigney [252(p. 116)]

Based on the critique in Chapter 3, the vast majority of quantitative Aboriginal and Torres Strait Islander health research continues to be founded in Western quantitative research methodologies and focussed on BADRR approaches [84, 330]. There appears to be an underlying notion that quantitative research in Aboriginal and Torres Strait Islander health research is exempt from Indigenous knowledges and methodologies [83, 84, 330]. These practices continue to colonise Aboriginal and Torres Strait Islander peoples and reinforce a deficit discourse, a discourse which plagues Aboriginal and Torres Strait Islander communities [83, 84, 330]. Specifically, for this thesis prior quantitative knowledge surrounding burns in Aboriginal and Torres Strait Islander children was focussed on dominant Western biomedical constructs [52, 63, 70, 74, 79, 82, 324-328]. To date, no quantitative burns research with Aboriginal and Torres Strait Islander children had engaged with Indigenous research methodologies, or principles of Indigenous data sovereignty [7, 83, 84, 145, 329, 330]. Instead, Aboriginal and Torres Strait Islander children were either reported with the 'dominant population', or as a subset of the dominant population [7, 83, 84, 145, 329, 330]. Furthermore, the Western biomedical focus of these studies often lacked health inequity contextualisation [52, 63, 70, 74, 79, 82, 324-328]. The studies in this thesis used Indigenous knowledges, knowledge interface methodologies and decolonisation methodologies as acts of resistance against the current Western biomedical research processes. Chapter 3 provided an overview of how I have used weaving as my process of resistance, to weave a knowledge interface into my studies. Through this process, Indigenous knowledges (knowing, being and doing) and Indigenous methodologies were woven together with Western research knowledge (epistemology, axiology and ontology) to produce a knowledge interface, which conformed to principles of mutual respect, shared benefits, human dignity and discovery [134]. Chapters 4, 5 and 7 contained studies which are specifically related to quantitative research, demonstrating how weaving a research methodology has been used as a way of resistance in burns research for Aboriginal and Torres Strait Islander children.

Recommendation 1

Quantitative research with any First Nations community, across any discipline, must engage and use Indigenous knowledges and research methodologies. This includes engagement with First Nations communities. These processes must occur from the outset - study conceptualisation, design, outcome analysis through to translation.

8.2.2 Decolonising Quantitative Measures

> *"The right of a [tribal] nation to govern the collection, ownership, and application of its own data".*
>
> US Indigenous Data Sovereignty Network [428(p. 732)]

Government and healthcare data repositories (ie epidemiological repositories, chronic condition registries, injury registries, health surveillance data, mortality databases) continue to be constructed from Western biomedical definitions and constructs of health and well-being [330, 428]. Whether it be through an unintentional implicit bias or cultural dissonance of governing/steering committees, excluding First Nations peoples and their voices from participating in these processes denies the sovereignty of First Nations people the opportunity to determine data and collection measurements that represent their health and well-being, including the interpretation, reporting and governing of this data [330, 428]. As such, these data repositories do not conform to Indigenous Data Sovereignty principles such as [84, 145, 330]:

- Indigenous data governance
- Indigenous leadership and representation on Registry Steering Committees
- Indigenous oversite determining: collection, access, analysis, interpretation, management, dissemination and reuse of data
- Indigenous quantitative methodologies
- Indigenous definitions and measures of health and well-being.

Currently there appears to be little to no agenda or will from these repositories to change or restructure their registries to conform to Indigenous data sovereignty principles. Not enacting principles of Indigenous data sovereignty, allows white possessive logic to control the space of data repositories for Aboriginal and Torres Strait Islander communities. Avoidance of engaging with these principles and practices acts against sovereignty, promotes colonisation and perpetuates the continued marginalisation of First Nations people, their health and well-being.

Recommendation 2

Data and surveillance registries with First Nation patients; must work with national peek First Nation community bodies and health professional networks to capture data for First Nation communities and work towards an agenda of Indigenous Data Sovereignty.

The International Classification of Health Interventions (ICHI), including the Australian modification (ACHI), also does little in recognising the sovereign rights of First Nations people. Rather, these classification systems focus on white possessive logic, only recognising knowledge which assists in reinforcing 'biopower' agendas and 'sovereign power', excluding and ignoring Indigenous knowledges which could assist in broadening understanding of First Nations' health and well-being [229, 232]. For example, the ICHI has a range of classifications related to 'Religion and Spirituality' and the ACHI contains classifications for 'spiritual care' under allied health, 'spiritual assessment', 'spiritual counselling', 'spiritual support' and 'spiritual ritual' which encompasses private prayer, worship, seasonal services, weddings and blessings [383, 429]. However, the ICHI has no classifications related to First Nations' cultural practices or interventions (ie First Nations health workers, marae, smudging, smoking etc). While the healthcare disciplines involved in establishing and monitoring these classifications may argue that these procedures fall under 'religion and spirituality', spirituality is only one dimension of the overall health and well-being of First Nations people. These classifications lack the recognition of important procedures related to the cultural health and well-being of First Nations peoples [116, 117]. This has been created through the dynamics of 'knowledge', 'power' and the 'discipline' where 'marginal knowledge' is ignored and not counted as 'truth' in the discipline [229, 232].

The ACHI in Australia has only one reference to Aboriginal and Torres Strait Islander peoples, in relation to Narrative Therapy as a procedure. The ACHI does not code for the important and unique roles of Aboriginal Health Practitioners, Aboriginal Health Workers or Aboriginal Liaison Workers with Aboriginal and Torres Strait Islander patients. Furthermore, data registries, such as BRANZ, do not provide additional classification or coding to recognise contact with these workers in Australia or New Zealand. While likely to be an unfortunate omission, these processes act as a form of disempowerment by the 'discipline', by not recognising the significant and important role that these health professionals play in the health and well-being of First Nations patients. Furthermore, it reinforces a colonial view of how tertiary health services are engaged with by Aboriginal and Torres Strait Islander peoples in Australia. From the studies of Chapters 4 and 5 of this thesis, it was unclear if Aboriginal and Torres Strait Islander children and their families were able to access these services, although it is possible to describe access to 'spiritual services'. With a lack of classification and coding for these workers in Australia, researchers, governments and hospitals have no appreciation if, or how, these services are being engaged with and utilised in the tertiary sector, especially in the context of

patient, disease and injury characteristics. This is a significant oversight given the critical nature of these services to the provision of culturally safe care for Aboriginal and Torres Strait Islander patients and their families.

Classification and coding for International Classification of Health Interventions (ICHI and ACHI) should be broadened to capture the unique health and well-being requirements of First Nations peoples. If this is unable to occur, government and health registries should instead broaden their coding and classification systems. This could start with registries auditing their coding and classification systems and engaging with reflexivity in the context of Indigenous data sovereignty. Where possible, broadening should be undertaken with First Nations Community Controlled Health Services through the inclusion of First Nations members on registry steering committees and establishing Indigenous reference groups who have oversight of steering committees.

Recommendation 3

International and Australian Classification of Health Interventions must broaden their knowledge for classifications and coding to ensure that the sovereign cultural health rights of First Nations people and their communities are recognised and captured.

Government and health registries should broaden their coding and classification systems and include First Nations peoples on their registry steering committees, through membership and Indigenous Reference group oversight.

Survey tools and questionnaires are commonly used in research and health settings to obtain quantitative information from Aboriginal and Torres Strait Islander patients, families and communities. They can take on a range of different forms. Chapter 2 focussed on two measures for HRQoL and Functions outcomes in children who had sustained an injury. Many of these tools have lacked quality assurance in their outcomes across various population groups (cultural, religious, injury type, disability, etc) as rigorous psychometric assessment in these population groups had not occurred. Additionally, as related to this thesis, the development and psychometric assessment of PROMs, specifically for Aboriginal and Torres Strait Islander communities, is reportedly to be rarely undertaken [399]. Rather, generic measures which have been developed from Western biomedical constructs of health and well-being are applied - actions which again disregard the sovereign health rights of First Nations peoples and are

colonising in their actions [145, 396]. In some cases, where psychometric assessment has occurred for measures, the focus is on Western quantitative processes where Indigenous Knowledge and methodologies are excluded [430]. Chapter 7 of this thesis has highlighted the inadequate nature of these processes: generic surveys and questionnaires should not be modified; rather, questionnaires and surveys should be built from the ground up, engaging with Aboriginal and Torres Strait Islander communities through the entire process of development through to psychometric assessment.

Recommendation 4

All questionnaires, surveys and patient-recorded outcome measures (ie HRQoL, psychological distress levels, etc) need to be decolonised and psychometrically assessed for appropriateness and use in any First Nations communities, across any life course.

8.2.3 Health Equity

"Eliminating Indigenous and ethnic health inequities requires addressing the social determinants of health inequities including institutional racism, in addition to ensuring a health care system that delivers appropriate and equitable care".

Associate Professor Elana Tai Curtis et al[431(p. 2)]
Te Kupenga Hauora Māori
Faculty of Medical and Health Sciences
University of Auckland

Injury burden is proportionally greater in children who face the greatest inequities [103]. Higher injury and mortality rates in children have been linked to lower levels of SES [217, 219-222]. Children from minority or culturally diverse backgrounds are reportedly overrepresented in this space [217]. However, childhood injury research still under-examines the impact of health inequities, as highlighted in the systematic review in this thesis (Chapter 2)[103]. A key component of this thesis was changing this focus, through comprehensively examining health inequities related to acute burns injuries in Aboriginal and Torres Strait Islander children. Stratifying BRANZ data by Aboriginal and Torres Strait Islander status was a key feature of this process so that analyses, which employed Indigenous knowledge and research methodologies, could be focussed on Aboriginal and Torres Strait Islander children. In conducting this analysis, we

found the profile for acute burns injury was different in Aboriginal and Torres Strait Islander children, compared to other Australian children. Remote residency, lower SES (ongoing impact of colonisation), injury severity (full thickness depth, bacterial infection) and longer hospital LOS was proportionally greater in Aboriginal and Torres Strait Islander children and represents persistent health inequities present in paediatric burns injuries in Australia (Chapter 4). Additionally, rural residency and full thickness burns were prognostic factors which contributed to longer hospital LOS for Aboriginal and Torres Strait Islander children, along with burns severity (flame, high %TBSA) and complex treatment requirements (split skin grafts)(Chapter 5). These prognostic factors and health inequities should indicate additional burden to clinical staff and healthcare teams working with Aboriginal and Torres Strait Islander families. Together, the combination promotes the establishment of financial strain and OOPHE which creates further marginalisation and induces poverty on Aboriginal and Torres Strait Islander families.

Recommendation 5

Injury research must prioritise the impact of health inequities. Research in this area should be underpinned by a health equity focus, from conceptualisation through to research translation, so that disenfranchised populations are not further marginalised. This includes engaging with key stakeholders and populations from the outset.

Aboriginal and Torres Strait Islander children and their families who present to hospital do not just present with a burns injury; they present with unique and different health inequities in conjunction with their burns injuries, in comparison to the dominant Australian population. These results are portrayed in Chapters 4, 5 and 6 and are equivalent to the qualitative work by my PhD colleagues and scholars on the Coolamon study. For example, the study in Chapter 5 demonstrated that Aboriginal and Torres Strait Islander children have a median hospital LOS four days longer than other Australian children. These results are indicative of my colleague (Fraser) who found that Aboriginal and Torres Strait Islander children from remote and residential areas were kept in hospital longer by clinicians, with one health worker reporting is was so “they’ll stay quiet … for the burn to heal” [351(p. 6)]. The results from Chapter 6 draw synergies to my other colleague’s (Coombes) work, who found that transport, family dislocation, racism and a lack of culturally safe care were the main themes impacting on Aboriginal and Torres Strait Islander families for burns aftercare [432]. Additionally, Coombes

reported that often parents and carers felt disempowered in the clinical setting and not part of any decision-making process for their child's burns aftercare [432]. These persistent themes, disempowerment and culturally unsafe care, reinforces health inequities and have been further reported in another colleague's (Williams) work, where Williams found that psychosocial interventions currently used in paediatric burns care did not consider the unique holistic health and well-being requirements of Aboriginal and Torres Strait Islander children [433].

While good clinical outcomes are important for the overall healing of a burns wound, it appears that this comes at the expense of the overall health and well-being of the Aboriginal and Torres Strait Islander child and their primary carers. Instead, this approach is either reinforcing or creating further health inequity burden. Burns injury treatment is stressful and taxing on any family, especially when children face months to years of ongoing treatment. When the health system or a health team is dismissive, and not reflexive or cognisant of the unique needs of Aboriginal and Torres Strait Islander families, culturally unsafe care ensues which reinforces marginalisation and broadens the health inequity gap [9, 27, 84, 113, 351, 355, 434-438]. Clinical teams and health professionals must be cognisant of these unique and different needs; they must engage with practices of cultural safety, such as decolonisation and reflexivity, when working in this space. Such actions focus on patient-centred care, while at the same time acting to decrease the burden that health inequities present. For instance, culturally safe care would see healthcare teams working closely with Aboriginal and Torres Strait Islander families (and their discharging healthcare facility) to decrease the impact of health inequities (ie hospital LOS, follow-up) and their manifestations (OOPHE), while at the same time ensuring desirable clinical outcomes can be met.

Health inequity impacts are not just exacerbated by treatment received at the tertiary point of care. Prevention programs, clinical guidelines, injury rehabilitation programs, surveillance and epidemiological repositories, education programs and government policy for burns injuries all must be conscious of these health inequities and adapt accordingly. While this requires radical change and rethinking; engagement with the multiple determinants of Indigenous health; Indigenous definitions of health and well-being; cultural safety and an understanding of the unique impacts of these health inequities will be important [68, 103, 352, 353]. For instance, the tailoring of burns prevention programs for Aboriginal and Torres Strait Islander communities across a range of residential locations (metropolitan, outer regional to remote) would be appropriate.

Recommendation 6

Prevention programs, clinical guidelines, injury rehabilitation programs and government policy must be reflexive in nature, providing scope and space for the incorporation of health inequities and factors which are specific to First Nations communities. Clinical staff should be supported to enact this through cultural safety.

8.2.4 Power

"War continues on within new mechanisms of power".

Aileen Morten-Robinson [439(p. 128)]

Children are a gift; they are strong and resilient in so many different ways and they have a basic right to be loved and cared for, so as to reach their full potential [6]. Despite this, there is vulnerability in their human rights through the violence and exploitation at the hands of adults. In 1982, the main human rights treaty, 'Convention on the Rights of the Child' was created, and was ratified in Australia [181]. In this treaty, every child is to be protected against all forms of discrimination, as well as having the right to appropriate healthcare and treatment in the event of injury or illness [181]. This treaty enshrines the rights of Aboriginal and Torres Strait Islander children and the protection of their cultural identity, health and well-being. For Aboriginal and Torres Strait Islander children, as outlined in Chapter 1, health is holistic in nature and underpinned by the multiple determinants of Indigenous health (self-determination, sovereignty, etc). Factors such as "healthy body, healthy mind", "relationships and support", "culture and identity" and "worries" have been identified as important to the health and well-being of Aboriginal and Torres Strait Islander children [7(p. 636)]. Despite the existence of these complex and diverse understandings of health and well-being for Aboriginal and Torres Strait Islander children, stereotyped norms - 'problematic', 'remote-alisation' and 'othering', created by the dominant Australian population (through discourse, media and research) continue to plague the way knowledge and research are engaged with in this space [7]. This is the interplay of power in Aboriginal and Torres Strait Islander health research.

The most insidious forms of power are invisible in nature. It is at this level that the domination and manipulation of power has become normalised and accepted [440]. In Australia, for Aboriginal and Torres Strait Islander communities and Indigenous knowledges, this is best theorised by distinguished Aboriginal scholar, Professor Aileen Moreton-Robinson as white

possessive logic [440, 441]. From Chapter 3, whiteness is the unnamed, invisible power and privilege of the dominant population [131, 134, 264] whereas possession is focussed on property rights, "values, beliefs, norms, social conventions and legal protection" [441(p. 20)]. In this way, white possession or white possessive logic is the invisible and normalised power and structures enacted and put in play by the dominant population, which take and deny Aboriginal and Torres Strait Islander people of their sovereignty and First Nations rights [440, 441]. In Chapter 3 of this thesis, white possessive logic in Aboriginal and Torres Strait Islander research was described through the "Western eurocentric hegemony of control, power and ownership" which has ensured that the 'status quo' from the dominant population remains [134]. This white possessive logic was evident in Chapter 2's systematic review outcomes, with the disciplinary knowledge of paediatric injury research - one which remains firmly focussed with a Western-dominant biomedical research lens [103]. The body of knowledge in this discipline excludes health inequity exploration [103]. In doing so, it allows children to be defined under a pan-dominant biomedical lens as a regulatory process, one where the treaty for children's rights are not recognised; one where diversity and discrimination do not exist [181, 442]. In this way, white possession ensures control and ownership, in that 'certain' children whom are not part of the dominant population remain invisible, and by remaining invisible disenfranchisement is strengthened [3, 103, 112, 138, 182, 183, 442].

Prior to the Coolamon study the narrative of burns for Aboriginal and Torres Strait Islander children, adults and communities was embedded in white possessive logic[52, 79, 82, 344, 443]. In this work the sovereign rights of Aboriginal and Torres Strait Islander communities had not been recognised[52, 79, 82, 344, 443]. No research had engaged with Indigenous knowledges or Aboriginal and Torres Strait Islander models of health and well-being [52, 79, 82, 344, 443]. Rather, burns disciplinary knowledge had been used to reinforce structural inequalities through the subjugation of Aboriginal and Torres Strait Islander communities (an ongoing act of colonisation)[439]. These research processes and outputs are culturally unsafe, colonising, create harm and highlight the continual, ongoing power dynamics in this research space[439, 440]. This thesis has resisted white possessive logic, engaging knowledge interface and decolonisation methodologies in research projects in Chapters 4, 5, 6 and 7. These methodologies and employed research methods have acted to challenge and counteract the disciplinary knowledge in this area, working against subjugation. This has not been without struggles and challenges against both whiteness and the discipline and this experience is captured further in my reflections.

Recommendation 7

Research with Aboriginal and Torres Strait Islander children and families must focus on the sovereign health and well-being rights of First Nations Australians. Research processes and agendas require radical change, to shift power dynamics and remove impacts of white possessive logic.

8.3 Strengths and Limitations

This thesis has exposed the significant depth and intensity of health inequities impacting on Aboriginal and Torres Strait Islander children who sustain an acute burns injury. Additionally, the exploration of OOPHE has provided insight into how health inequity manifestations impact on Aboriginal and Torres Strait Islander families and the complexities of measuring this manifestation. A substantial strength of this work was the research methodology employed, knowledge interface methodology. By weaving a research interface (Chapter 3), this ensured that Indigenous knowledges were employed alongside Western quantitative knowledges. This is a real first in the area of injury epidemiology and is likely to challenge the white possessive logic in this space. Another strength of this research is the number of Aboriginal people who have contributed to it; this body of work was undertaken by an Aboriginal researcher, supported by an Aboriginal supervisor, Aboriginal Chief Investigators and reference group members of the Coolamon study and other Aboriginal doctoral students. This has assisted in ensuring that the four principles of knowledge interface methodology: mutual respect, shared benefits, human dignity and discovery were met. Additionally, while the focus of this study was on burns injuries, the outcomes from this research are likely to be transferable across multiple illnesses and injuries and First Nations communities globally.

However, this body of work is only a drop in the ocean in terms of what needs to be done and what needs to change, and as such there are limitations to the research. Apart from Chapter 6, which was a scoping examination, the majority of this research is quantitative. As such, a quantitative focus only captures the numbers of the narrative. There is a whole body of qualitative work which needs to be undertaken to broaden and contextualise the understanding of health inequities and their impact on Aboriginal and Torres Strait Islander family's whose child has sustained an acute burns admission.

The BRANZ captures data from seventeen reporting hospitals in Australia and New Zealand, all of which are tertiary facilities and not all of these hospitals have been reporting for the same

amount of time. This research does not reflect the experience of Aboriginal and Torres Strait Islander families who have been treated at primary or secondary healthcare facilities for their burns injuries. Additionally, this research focussed on initial acute burns injury admissions only, therefore this research only captures one treatment point in time - the initial admission. It does not reflect the experience of multiple admissions or rehospitalisation which are common in the treatment of severe acute burns injuries.

The BRANZ is a Western biomedically constructed epidemiological repository, where colonial constraints and whiteness are present and unacknowledged [83, 330]. While knowledge interface methodology has been employed, allowing for an Indigenous Knowledge focus, this bias is a limitation for studies in Chapters 5 and 6. Additionally, registries of this type are predisposed to under-reporting and identification of Aboriginal and Torres Strait Islander children [63, 354]. This is a limitation of the research conducted in Chapters 5 and 6 of this thesis.

The work surrounding OOPHE in Aboriginal families is preliminary, with a very small pool of study participants for both Chapters 6 and 7. A better appreciation of the nuanced effects of financial burden, thrust upon Aboriginal families through OOPHE, is needed across a range of illnesses, injuries and life courses. Further work is required, with a much larger participant group, to obtain a comprehensive understanding of the nuanced and multi-dimensional impacts of OOPHE. This may take the form of a large longitudinal-based study with Aboriginal and Torres Strait Islander families. This work should include determining the most appropriate ways to measure and assess OOPHE with Aboriginal and Torres Strait Islander families. The research provided in Chapters 6 and 7 of this thesis provides essential outcomes and a solid foundation for future research.

8.4 Personal Reflection

"I don't have hope, I think you create hope".

Nakkiah Lui[444]

Aboriginal actor, writer and comedian

Co-writer and star of Black Comedy

When I was in primary school I have this memory of telling my parents I wanted to be a vet when I grew up. My mum responded by telling me that vets were smart people, they went to university and had to be very good at maths, perhaps I should think about something else. Now, before you jump to the conclusion that my parents were terrible people for not telling me to reach for the stars, let me give you a little context here. I was brought up in rural Australia, people didn't go on to study at university unless they came from one of the rich farming families or businesses. We were not rich, no one had really gone to University in my family, so this was not the reality for a young Aboriginal girl. Funny thing is, turns out I was alright at maths and science at school. In high school I had my heart firmly set on becoming a biomedical engineer because I wanted to make prosthetics for individuals who had lost limbs through diabetes as it was something that had impacted my family tremendously. However, in my final year I have the memory of one of my teachers telling me to give up, I wasn't good enough to get in to university, perhaps I needed to set my sights on something a little lower. After all, how many Aboriginal engineers were there in Australia?

In March 2006 I graduated from biomedical engineering, a double degree in science, engineering with honours. As an undergrad I volunteered each summer to be a peer mentor at the Indigenous Australian Engineering Summer Schools, held at the University of New South Wales at that time. I had the privilege of mentoring 100+ Aboriginal and Torres Strait Islander high school students. Telling them to reach for the stars, that they could achieve anything they wanted to and to not let anyone tell them they couldn't. So many students who I had the privilege to mentor have gone on to become amazing professionals across a wide range of fields. I am still involved with engineering through the Indigenous Engineering Group Executive and Engineering Aid. During my studies and these experiences I felt drawn to the tertiary academy, with an interest in being a balanced academic in both teaching and research. It was always my intention to work in injury and rehabilitation research, to use my skills to improve health outcomes for Aboriginal and Torres Strait Islander communities. I started my academic career early on in the tertiary space, often being mistaken as a student at staff meetings. Like

so many Aboriginal academics starting off in the academy, I was exploited. My role became very firmly stuck in teaching, administration, student admissions and support. There was no room to start my injury research desires; additionally, there was no support to assist me in doing this.

Time went on …. a dear friend moved back from the West, a friend who I always knew would supervise my PhD. I married my partner in crime, started a family, and it was at this point that things changed; the time was right for me to go on this journey. Some would say the stars aligned, or the ancestors had spoken. Now I am here, nearing the end of my journey, so much has occurred both personally and professionally that I am speechless … do I even recognise my reflection at the beginning, or of that young girl who wanted to be a vet?

> ***"I am a child of the Dreamtime People***
> ***Part of this land, like the gnarled gumtree…"***
>
> ***"..I'm the snow, the wind and the falling rain***
> ***I'm part of the rocks and the red desert earth***
> ***Red as the blood that flows in my veins***
> ***I am eagle, crow and snake that glides"***
>
> Spiritual Song of the Aborigine (sic.)
> by Hyllus Maris [4(p. 2)]

Yes, I am currently recognised as an emerging Aboriginal researcher in injury. But it is so critical to point out that I am Aboriginal first and researcher second. This is something that can never be changed. It is so important as it is also part of the way that I conduct myself, my value system, the way that I approach and do business in research and teaching. My experiences as an Aboriginal person doing a doctorate are like so many other Aboriginal academics in this space - the similarities are almost identical in nature. This is hard because the reality hits - that in Australia we have so far to come in this space.

When you first enter the higher degree tertiary education program, it is so exciting. You have this fantasy that you are moving into a highly intellectual and learned space, one where whiteness, racism, bullying and discrimination do not exist, because everyone gets it!! Such a lovely fantasy, which doesn't last too long. What you do learn is that whiteness and

racism…well, they are insidious and invisible, especially to the perpetrator (who generally feels they hold all the knowledge, or are the victim). Racism and whiteness also love coming out to work when power structures and politics are at play. The worst case I experienced was the racism and bullying from a professor on one of my studies. I was directed by my primary supervisor to bring this professor on as an author on my manuscript for this study, which I of course did. The result was months of back and forth feedback on my manuscript. The feedback was bullying in nature, demonstrating a lack of knowledge of Aboriginal and Torres Strait Islander health, but also no reflexivity on their behalf. The comments really highlighted the power dynamics at play and the grips of white possessive logic in this area. This time was emotionally hard and traumatising for me; first as an Aboriginal person, I was being constantly attacked, being put down; with insinuating undertones that I had no idea what I was doing, that I didn't belong in this space, that I was not good enough. All at a time when I was trying to train and learn to be a researcher. It is this experience that triggers the internalised racism and bullying in your head, those dark voices, 'you are not good enough', 'you do not belong here', 'you got no idea' and 'just drop out'. I drew support from my Aboriginal colleagues during this time, and my husband. As the situation escalated, it took my Aboriginal supervisor to step in to address the situation and the constant attacks.

> *"As Aboriginal people … We often have to wear the prejudices of those we are working with as well as bear the brunt of educating them".*
>
> Associate Professor Tamara Mackean

The result of this situation was that this professor came off the paper, but there was no admission or reflection on their behalf as being an instigator of bullying or racism, which is sad as it demonstrates a lack of growth on their behalf. What is concerning is that this professor could continue to engage and publish in the space of Aboriginal and Torres Strait Islander health and instigate this inappropriate behaviour, behaviour that works against the National Health and Medical Research Council guidelines for engagement in Aboriginal and Torres Strait Islander health research. While I will forever be thankful to Tamara for stepping in and calling this situation out for what it was, she was the only person who did this. My only Aboriginal supervisor had to stand up for my rights as an Aboriginal student. Hopefully in the future this will change, where non-Aboriginal supervisors, regardless of friendships or relationships, will be able to stand up for the rights of their Aboriginal students and call out academics on their

bullying and racist behaviours, rather than making excuses and supporting their poor and unprofessional behaviour.

Unfortunately, these experiences build up and provide an additional burden through the vicarious trauma that we experience as Aboriginal researchers. Vicarious trauma, is described by Aboriginal researcher, Anne-Marie Eades, "*through which the therapist's inner experience is negatively transformed through empathic engagement with clients' traumatic material*" [445(p.2)]. While some may reflect that this occurs more commonly in qualitative research, the experience can also be real for quantitative research. Even in the data sets that I work with, each of those numbers represent an Aboriginal and/or Torres Strait Islander child who has had their health and well-being impacted upon. Also, I am tired of reading journals which have been undertaken by non-Aboriginal research teams, making grave generalisations and analyses on our data. These experiences are part of the vicarious trauma that I have experienced. The most challenging vicarious trauma that I experienced was after Yarning sessions with Aboriginal families about OOPHE. Families openly shared their family's burns injury story with me, the pain and grief so evident. The emotions, feelings of distress from their lived experience, in parts, so closely resembled those of my own growing up. That pitted feeling of hopelessness, that you could not change or make things right for these families was sickening, because you had visions that this was never going to get better. During this time, I used reflexivity as a tool to help work through my feelings and emotions, and to stop personal triggers. Often, I would have a yarn with the other Aboriginal PhD students on the Coolamon study, or my Aboriginal work colleagues at Flinders University. Even if just a debrief, or working through the triggers; in these ways we looked after each other, working through our vicarious trauma together.

"I am the river, softly singing
Chanting our songs on my way to the sea
My spirit is the dust-devils
Mirages, that dance on the plain".

Spiritual Song of the Aborigine (sic.)
by Hyllus Maris [4(p. 2)]

Before starting my PhD journey, I was accepted to attend the inaugural Indigenous PhD Familiarisation Program, run by the Poche Centre at the University of Melbourne. This was a

truly amazing experience. I met a range of Aboriginal students who wanted to start the PhD journey. We also were mentored by inspiring Aboriginal and Torres Strait Islander academics and leaders: Professor Marcia Langton, Professor Ian Anderson, Professor Kerry Arabena, Professor Shaun Ewen, just to name a few. They gave us so much time, sharing their PhD stories and journey, reinforcing that our standpoint and identity as an Aboriginal person was important, that it counted and will always be part of the research work that we do.

One of the most beautiful journeys that I was able to go on for my PhD was the development of my own research methodology – using weaving as an approach to create a knowledge interface for my studies. Having the time to sit, read and draw on the work of other Aboriginal and Torres Strait Islander scholars was so important for the development of my standpoint, but also for providing me with the strength that I needed for this journey. I was also lucky enough to attend a week-long workshop on Indigenous research methodologies run by Associate Professor Simone Ulalka Tur (PVC-Indigenous) and Dr Ali Gumyilla Baker at Flinders University. This program was all-inspiring and so important in building my strength, resilience and sovereignty as an Aboriginal researcher. They also provided me with the tools of resistance, to enact against the status quo of quantitative research and the academy.

"Through the rainforest that clings to the mountainside
I awakened here when the earth was new
There was emu, wombat, kangaroo
No other man of a different hue
I am this land
And this land is me".

Spiritual Song of the Aborigine (sic.)
by Hyllus Maris [4(p. 2)]

My PhD journey has probably taught me more about myself than I realise. Yes, I have learnt skills to become a researcher, but I have also learnt a lot about myself. When I think back now to that girl who was discouraged to become a vet and engineer. What I hope I have been able to show her is that we are not a deficit discourse or narrative. This is not who we are as Aboriginal people and it should never, ever be used to define our identity. As Aboriginal people we are strong and resilient, we can create a path and journey for wherever we would like to

go, but in creating that path, we must create it well so that others can easily follow and extend it.

8.5 Concluding Remarks

This thesis provides the first detailed quantitative health inequity analyses of acute burns injuries in Aboriginal and Torres Strait Islander children. Additionally, this thesis also provides the first scoping exploration of OOPHE, a health inequity manifestation, impacting Aboriginal and Torres Strait Islander families with extensive hospital LOS for their child's acute burn injury. A fundamental strength of this research is the engagement with the knowledge interface methodology, through weaving a research interface. This methodology has ensured that both Indigenous knowledges and Western quantitative research knowledges have been used in a partnership focussed on honesty, ethical conduct, mutual respect and protection, so that research outcomes are there to benefit Aboriginal and Torres Strait Islander communities. As such, this thesis provides the most up to date and relevant information on burns injuries from an Aboriginal perspective, which will significantly advance knowledge and understanding in the space of burns, and injuries more broadly, in Aboriginal and Torres Strait Islander children.

The outcomes from this thesis present a range of health inequity impacts on Aboriginal and Torres Strait Islander children and families facing treatment for burns injuries. This includes remote residency, lower SES (from ongoing colonisation), increased burns severity (full thickness depth, bacterial infection) and a median hospital LOS four days longer than other Australian children. These factors, along with treatment options (split skin graft, debridement, allied health intervention), flame burns and high %TBSA are prognostic factors increasing hospital LOS for Aboriginal and Torres Strait Islander children. All are proportionally greater in Aboriginal and Torres Strait Islander children when compared to other Australian children, highlighting the clear and inadequate health inequities impacting Aboriginal and Torres Strait Islander children and their families.

The collective amalgamation of these health inequities manifests in many ways, such as OOPHE, which only serves to cause further marginalisation and disenfranchisement of Aboriginal and Torres Strait Islander families. Aboriginal families are impacted financially through OOPHE for their child's burns injury treatment and rehabilitation. Contextualisation of these health inequities, their manifestation and the unique and different needs of Aboriginal

and Torres Strait Islander children and their families must be integrated into prevention and educational programs, clinical guidelines, treatment and rehabilitation programs and government policy. Additional support mechanisms must be considered so that Aboriginal and Torres Strait Islander families can receive the best possible care for their child's burns injury, but not at the risk of further marginalisation, financial hardship or poverty.

While focussed on burns injuries in Aboriginal and Torres Strait Islander children, this body of work identified that power dynamics, such as white possessive logic, fundamentally control knowledge in this space. This body of work has resisted falling into this invisible, normalised framework of research, instead providing a different narrative, imbedded in Indigenous knowledges. However, within this work, it was further identified that principles working towards Indigenous Data Sovereignty in burns research were not apparent. Radical change is required by government and Western epidemiological data repositories collecting data on Aboriginal and Torres Strait Islander communities. I have provided suggestions on how Indigenous Data Sovereignty could be achieved in this space, from governance representation through to treatment coding. This also extends to quantitative measurement tools used in Aboriginal and Torres Strait Islander families. Modification of pre-existing tools designed around Western biomedical constructs and understandings are not appropriate. I recommend that quantitative measures be developed with Aboriginal and Torres Strait Islander families from the outset, so that they can include important contextual factors for Aboriginal and Torres Strait Islander communities.

CHAPTER 9

9.1 References

1. Durie M. Exploring the interface between science and Indigenous knowledge. 2004:
2. Bessarab D, Ng'andu B. Yarning about yarning as a legitimate method in Indigenous research. *International Journal of Critical Indigenous Studies*. 2010;3(1):37-50.
3. Welch V, Petticrew M, Tugwell P, et al. PRISMA-Equity 2012 extension: reporting guidelines for systematic reviews with a focus on health equity. *Revista Panamericana de Salud Pública*. 2013;34(1):60-67.
4. Mafi-Williams L. *Spirit Song: A Collection of Aboriginal Poetry*. Omnibus Books; 1993.
5. Pascoe B. *Dark Emu Black Seeds: Agriculture or accident?* Magabala Books; 2014.
6. Milroy H. Chapter 12: Children Are Our Future - Understanding the Needs of Aboriginal Children and Their Families. In: Williams A, Cowling V, eds. *Infants of Parents with Mental Illness : Developmental, Clinical, Cultural and Personal Perspectives*. Australian Academic Press; 2008:121-140.
7. Priest N, Thompson L, Mackean T, Baker A, Waters E. 'Yarning up with Koori kids'– hearing the voices of Australian urban Indigenous children about their health and well-being. *Ethnicity and Health*. 2017;22(6):631-647.
8. Australian Institute of Health and Welfare. *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015*. 2015. IHW 147.
9. Walter M. Social exclusion/inclusion for urban Aboriginal and Torres Strait Islander people. *Social Inclusion*. 2016;4(1):68-76.
10. Department of Social Services. *Longitudinal Study of Indigenous Children – Key Summary Report from Wave 5*. 2015. https://www.dss.gov.au/
11. Priest NC, Paradies YC, Gunthorpe W, Cairney SJ, Sayers SM. Racism as a determinant of social and emotional wellbeing for Aboriginal Australian youth. Article. *Medical Journal of Australia*. 2011;194(10):546-550.
12. Commonwealth of Australia. *Department of the Prime Minister and Cabinet, Closing the Gap: Prime Minister Report 2018*. 2018.
13. Marmor A, Harley D. What promotes social and emotional wellbeing in Aboriginal and Torres Strait Islander children?: Lessons in measurement from the Longitudinal Study of Indigenous Children. *Family Matters*. 2018;(100):4-18.
14. Girasek DC. Would society pay more attention to injuries if the injury control community paid more attention to risk communication science? *Injury prevention : journal of the International Society for Child and Adolescent Injury Prevention*. 2006;12(2):71-73.
15. Peden M, Oyegbite K, Ozanne-Smith J, et al. *World report on child injury prevention*. World Health Organization; 2008:1-232.
16. Pinheiro PS. *World report on violence against children*. United Nations Secretary-General's study on violence against children; 2006:1-19.
17. Sleet DA. The Global Challenge of Child Injury Prevention. *International journal of environmental research and public health*. 2018;15(9):1921.
18. Gallagher S, Finison K, Guyer B, Goodenough S. The incidence of injuries among 87,000 Massachusetts children and adolescents: results of the 1980-81 Statewide Childhood Injury Prevention Program Surveillance System. *American journal of public health*. 1984;74(12):1340-1347.
19. Polinder S, Haagsma J, Toet H, van Beeck E. Epidemiological burden of minor, major and fatal trauma in a national injury pyramid. *British Journal of Surgery*. 2012;99(S1):114-120.
20. Alonge O, Hyder A. Reducing the global burden of childhood unintentional injuries. *Archives of disease in childhood*. 2014;99(1):62-69.

21. Birken CS, Macarthur C. Socioeconomic status and injury risk in children. *Paediatrics & child health*. 2004;9(5):323-325.
22. Poulos R, Hayen A, Finch C, Zwi A. Area socioeconomic status and childhood injury morbidity in New South Wales, Australia. *Injury Prevention*. 2007;13(5):322.
23. Laflamme L, Hasselberg M, Burrows S. 20 Years of Research on Socioeconomic Inequality and Children's—Unintentional Injuries Understanding the Cause-Specific Evidence at Hand. *International Journal of Pediatrics*. 2010;2010
24. Jiang X, Li D, Boyce W, Pickett W. Variations in injury among Canadian adolescents by urban-rural geographic status. *Chronic Diseases in Canada*. 2007;28(1-2):56-62.
25. Mitchell R, Curtis K, Foster K. *A 10-year review of the characteristics and health outcomes of injury-related hospitalisations of children in Australia*. University of Sydney; 2017.
26. Pointer S. *Hospitalised injury in children and young people 2011-12*. AIHW; 2014. *Injury research and statistics series no 91*. Cat. no. INJCAT 167.
27. McGarry S, Elliott C, McDonald A, Valentine J, Wood F, Girdler S. "This is not just a little accident": a qualitative understanding of paediatric burns from the perspective of parents. *Disabil Rehabil*. 2015;37(1):41-50.
28. Sengoelge M, El-Khatib Z, Laflamme L. The global burden of child burn injuries in light of country level economic development and income inequality. *Preventive Medicine Reports*. 2017;6:115-120.
29. Brusselaers N, Monstrey S, Vogelaers D, Hoste E, Blot S. Severe burn injury in Europe: a systematic review of the incidence, etiology, morbidity, and mortality. *Critical Care*. 2010;14(5):R188.
30. Dissanaike S, Rahimi M. Epidemiology of burn injuries: highlighting cultural and socio-demographic aspects. *International Review of Psychiatry*. 2009;21(6):505-511.
31. Shah A, Suresh S, Thomas R, Smith S. Epidemiology and profile of pediatric burns in a large referral center. *Clinical Pediatrics*. 2011;50(5):391-395.
32. Iqbal T, Saaiq M. The burnt child: an epidemiological profile and outcome. *Coll Physicians Surg Pakistan*. 2011;21(11):691-4.
33. Battle CE, Evans V, James K, et al. Epidemiology of burns and scalds in children presenting to the emergency department of a regional burns unit: a 7-year retrospective study. *Burns*. 2016;4(1):19.
34. Baker R, Orton E, Tata LJ, Kendrick D. Epidemiology of poisonings, fractures and burns among 0–24 year olds in England using linked health and mortality data. *The European Journal of Public Health*. 2016;26(6):940-946.
35. Spinks A, Wasiak J, Cleland H, Beben N, Macpherson AK. Ten-year epidemiological study of pediatric burns in Canada. *Journal of Burn Care and Research*. 2008;29(3):482-488.
36. Atlantic Collaborative on Injury Prevention and Child Safety Link. *Child & Youth Unintentional Injury: 10 Years in Review 2004-2013*. Child Safety Link; 2016.
37. James SL, Lucchesi LR, Bisignano C, et al. Epidemiology of injuries from fire, heat and hot substances: global, regional and national morbidity and mortality estimates from the Global Burden of Disease 2017 study. *BMJ Injury Prevention*. 2019;(0):1-10.
38. Smolle C, Cambiaso-Daniel J, Forbes AA, et al. Recent trends in burn epidemiology worldwide: A systematic review. *Burns*. 2017;43(2):249-257.
39. Duke JM, Rea S, Boyd JH, Randall SM, Wood FM. Mortality after burn injury in children: a 33-year population-based study. *Pediatrics*. 2015;135(4):e903-e910.
40. Weedon M, Potterton J. Socio-economic and clinical factors predictive of paediatric quality of life post burn. *Burns*. 2011;37(4):572-579.
41. McGarry S, Elliott C, McDonald A, Valentine J, Wood F, Girdler S. Paediatric burns: from the voice of the child. *Burns*. Jun 2014;40(4):606-15.
42. MacKean G, Doherty T, Metcalfe A. *Raising Canada: A report on children in Canada, their health and wellbeing*. University of Calgary; 2018.

43. Borse N, Gilchrist J, Dellinger A, Rudd R, Ballesteros M, Sleet D. *CDC Childhood Injury Report: Patterns of Unintentional Injuries among 0 -19 Year Olds in the United States 2000-2006* Centers for Disease Control and Prevention. National Center for Injury Prevention and Control; 2008.
44. Safekids-Aotearoa. *Child Unintentional Deaths and Injuries in New Zealand, and Prevention Strategies*. NZ: Safekids Aotearoa; 2015.
45. Wasiak J, Spinks A, Ashby K, Clapperton A, Cleland H, Gabbe B. The epidemiology of burn injuries in an Australian setting, 2000–2006. *Burns*. 2009;35(8):1124-1132.
46. Miller SF, Bessey PQ, Schurr MJ, et al. National Burn Repository 2005: A Ten-Year Review. *Journal of Burn Care and Research*. 2006;27(4):411-436.
47. Wang T, Nie C, Zhang H, et al. Epidemiological characteristics and factors affecting length of hospital stay for children and adults with burns in Zunyi, China: A retrospective study. Article. *PeerJ*. 2018;2018(10)e5740.
48. Hop MJ, Polinder S, van der Vlies CH, Middelkoop E, van Baar ME. Costs of burn care: a systematic review. *Wound Repair & Regeneration*. 2014;22(4):436-450.
49. Seah R, Holland A, Curtis K, Mitchell R. Hospitalised burns in children up to 16 years old: A 10 ‐ year population ‐ based study in Australia. *Journal of Paediatrics and Child Health*. 2018;55(9):1084-1090.
50. Tracy T, McInnes J, Gong J, Karunakaran R, Gabbe B. *Burns Registry of Australia and New Zealand 9th Annual Report*. 2019.
51. Tracy L, McInnes J, Gong J, Gabbe B, Thomas T. *Burns Registry of Australia and New Zealand Annual Report July 2016 - July 2017*. Monash University; 2017. 8th Annual Report.
52. Riedlinger DI, Jennings PA, Edgar DW, et al. Scald burns in children aged 14 and younger in Australia and New Zealand—an analysis based on the Burns Registry of Australia and New Zealand (BRANZ). *Burns*. 2015;41(3):462-468.
53. de Silva H, Gabbe B, Callaghan J, Liman J. *Burns Registry of Australia and New Zealand Annual Report July 2013 – June 2014*. Monash University; 2014. 5th Annual Report.
54. Maskell J, Newcombe P, Martin G, Kimble R. Psychosocial Functioning Differences in Pediatric Burn Survivors Compared With Healthy Norms. *Journal of Burn Care and Research*. 2013;34(4):465-476.
55. Jastrowski Mano KE, Khan KA, Ladwig RJ, Weisman SJ. The impact of pediatric chronic pain on parents' health-related quality of life and family functioning: reliability and validity of the PedsQL 4.0 Family Impact Module. *Journal of Pediatric Psychology*. Jun 2011;36(5):517-27.
56. Sheridan RL, Lee, A.F., Kazis, L.E., Liang, M.H., Li, N.C., Hinson, M.I., Bauk, H., Meyer III, W.J., Stubbs, T.K., Palmieri, T.L. Tompkins, R.G. The effect of family characteristics on the recovery of burn injuries in children. *Journal of Trauma and Acute Care Surgery*. 2012;73(3):S205-S212.
57. Landolt MA, Grubenmann S, Meuli M. Family Impact Greatest: Predictors of Quality of Life and Psychological Adjustment in Pediatric Burn Survivors. *Trauma*. 2002;53(6):1146-1151.
58. Spronk I, Van Loey NE, Sewalt C, et al. Recovery of health-related quality of life after burn injuries: An individual participant data meta-analysis. *PLoS One*. 2020;15(1):e0226653.
59. Spronk I, Legemate CM, Dokter J, van Loey NEE, van Baar ME, Polinder S. Predictors of health-related quality of life after burn injuries: a systematic review. *Critical Care*. 2018;22(1):160.
60. Baker RAU, Jones S, Sanders C, et al. Degree of Burn, Location of Burn, and Length of Hospital Stay as Predictors of Psychosocial Status and Physical Functioning. *The Journal of Burn Care and Rehabilitation*. 1996;17(4):327-333.
61. O'Brien KH, Lushin V. Examining the Impact of Psychological Factors on Hospital Length of Stay for Burn Survivors: A Systematic Review. *Journal of Burn Care and Research*. 2018;40(1):12-20.

62. Dyson K, Cameron W, Gabbe B, Thomas T. *Burns Registry of Australia and New Zealand Annual Report July 2015 - June 2016*. Vol. 7th. Monash Unversity; 2015. 7th Annual Report.
63. Möller H, Harvey L, Falster K, Ivers R, Clapham KF, Jorm L. Indigenous and non-Indigenous Australian children hospitalised for burn injuries: a population data linkage study. *Medical Journal of Australia*. 2017;206(9)(206):392-397.
64. Matin BK, Rezaei S, Karyani AK. Factors associated with length of stay and hospital charges among pediatric burn injury in Kermanshah, west of Iran. Article. *International Journal of Pediatrics*. 2015;3(1):403-409.
65. Elrod J, Schiestl CM, Mohr C, Landolt MA. Incidence, severity and pattern of burns in children and adolescents: An epidemiological study among immigrant and Swiss patients in Switzerland. Article. *Burns*. 2019;45(5):1231-1241.
66. Gabbe B, Picton N, Loh N, Watterson D. *Bi-National Burns Registry Annual Report Jul 2011 - Jun 2012*. Monash University; 2012. 3rd Annual Report.
67. Pointer S, Tovell A. *Hospitalised burn injuries - Australia 2013–14.* AIHW; 2016. *Injury research and statistics series no 102* Cat. no. INJCAT 178.
68. Möller H, Falster K, Ivers R, Clapham K, Harvey L, Jorm L. High rates of hospitalised burn injury in Indigenous children living in remote areas: a population data linkage study. Letter. *Australian and New Zealand Journal of Public Health*. 2018;42(1):108-109.
69. Duke J, Wood F, Semmens J, et al. A Study of Burn Hospitalizations for Children Younger Than 5 Years of Age: 1983–2008. *Pediatrics*. 2011;127(4):e971-e977.
70. Duke J, Wood F, Semmens J, et al. A 26-year population-based study of burn injury hospital admissions in Western Australia. *Journal of Burn Care and Research*. 2011;32(3):379-386.
71. Hyland EJ, Zeni G, Harvey JG, Holland A. Rural and metropolitan pediatric burns in New South Wales and the Australian Capital Territory: does distance make a difference? *Journal of Burn Care and Research*. 2015;36(4):e231-e237.
72. Rajan V, Abeyasundara SL, Harvey JG, Holland AJA. Exhaust burns in children. *Burns*. 2011;37(2):273-276.
73. Abeyasundara SL, Rajan V, Lam L, Harvey JG, Holland AJ. The changing pattern of pediatric burns. *Journal of Burn Care and Research*. 2011;32(2):178-184.
74. Okon O, Zhu L, Kimble RM, Stockton KA. A review of campfire burns in children: The QLD experience. *Burns*. 2018;44(5):1317-1321.
75. Ivers RQ, Hunter K, Clapham K, et al. Understanding burn injuries in Aboriginal and Torres Strait Islander children: protocol for a prospective cohort study. *BMJ Open*. 2015;5(10):e009826.
76. Möller H, Ivers R, Clapham K, Jorm L. Are we closing the Aboriginal child injury gap? A cohort study. Article. *Australian and New Zealand Journal of Public Health*. 2019;43(1):15-17.
77. Department of Social Services. *Longitudinal Study of Indigenous Children – Key Summary Report from Wave 2*. 2011. https://www.dss.gov.au/
78. Department of Social Services. *Longitudinal Study of Indigenous Children – Key Summary Report from Wave 1*. 2009. https://www.dss.gov.au/
79. Read DJ, Tan SC, Ward L, McDermott K. Burns first aid treatment in remote Northern Australia. *Burns*. 2018;44(2):481-487.
80. Meshulam-Derazon S, Nachumovsky S, Ad-El D, Sulkes J, Hauben DJ. Prediction of morbidity and mortality on admission to a burn unit. Article. *Plastic and Reconstructive Surgery*. 2006;118(1):116-120.
81. Duke J, Wood F, Semmens J, Edgar D, Spilsbury K, Rea S. An assessment of burn injury hospitalisations of adolescents and young adults in Western Australia, 1983–2008. *Burns*. 2012;38(1):128-135.
82. Murphy L, Read D, Brennan M, Ward L, McDermott K. Burn injury as a result of interpersonal violence in the Northern Territory Top End. *Burns*. 2019;45(5):1199-1204.

83. Walter M, Andersen C. *Indigenous Statistics: A Quantitative Research Methodology*. Left Coast Press; 2013.
84. Walter M. The voice of Indigenous data: Beyond the markers of disadvantage. *Griffith Review*. 2018;(60):256.
85. Strega S, Brown L. *Research as Resistance: Revisiting Critical, Indigenous and Anti-Oppressive Approaches*. 2nd ed. Canadian Scholars' Press Women's Press; 2015.
86. National Health and Medical Research Council. *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*. National Health and Medical Research Council; 2018.
87. National Health and Medical Research Council. *Keeping research on track II: A companion document to ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders* National Health and Medical Research Council; 2018.
88. Zabel M, Stevens D. What happens to health care quality when the patient pays? : BMJ Publishing Group Ltd; 2006.
89. National Academies of Sciences E, Medicine. *Communities in action: Pathways to health equity*. National Academies Press; 2017.
90. Dahlgren G, Whitehead M. Policies and strategies to promote social equity in health. *Stockholm: Institute for future studies*. 1991;27(1):4-41.
91. Marmot M, Ryff CD, Bumpass LL, Shipley M, Marks NF. Social inequalities in health: next questions and converging evidence. *Journal of Social Science Medicine*. 1997;44(6):901-910.
92. Marmot MG, Stansfeld S, Patel C, et al. Health inequalities among British civil servants: the Whitehall II study. *The Lancet*. 1991;337(8754):1387-1393.
93. World Health Organisation. Social Determinants of Health. WHO. Accessed 5/09/2019, https://www.who.int/social_determinants/en/
94. Viner RM, Ozer EM, Denny S, et al. Adolescence and the social determinants of health. *The Lancet*. 2012;379(9826):1641-1652.
95. Ahmed S, Creanga AA, Gillespie DG, Tsui AO. Economic status, education and empowerment: implications for maternal health service utilization in developing countries. *PloS one*. 2010;5(6):e11190.
96. Cho YI, Lee S-YD, Arozullah AM, Crittenden KS. Effects of health literacy on health status and health service utilization amongst the elderly. *Social Science Medicine*. 2008;66(8):1809-1816.
97. Benach J, Vives A, Amable M, Vanroelen C, Tarafa G, Muntaner C. Precarious Employment: Understanding an Emerging Social Determinant of Health. *Annual Review of Public Health*. 2014/03/18 2014;35(1):229-253.
98. Phillips SP. Defining and measuring gender: A social determinant of health whose time has come. *International Journal for Equity in Health*. 2005/07/13 2005;4(1):11.
99. Baker E, Lester LH, Bentley R, Beer A. Poor housing quality: Prevalence and health effects. *Journal of Prevention & Intervention in the Community*. 2016;44(4):219-232.
100. McIntyre L. Food security: more than a determinant of health. *Policy Options-Montreal*. 2003;24(3):46-51.
101. Foley W, Ward P, Carter P, Coveney J, Tsourtos G, Taylor A. An ecological analysis of factors associated with food insecurity in South Australia, 2002–7. *Public Health Nutrition*. 2010;13(2):215-221.
102. Pollard CM, Booth S. *Addressing Food and Nutrition Security in Developed Countries*. Multidisciplinary Digital Publishing Institute; 2019.
103. Ryder C, Mackean T, Hunter K, et al. Equity in functional and health related quality of life outcomes following injury in children - a systematic review. *Critical Public Health*. 2019;30(3):352-366.

104. Braveman P, Gruskin S. Defining equity in health. *Journal of Epidemiology and Community Health*. 2003;57(4):254-258.
105. Welch VA, Petticrew M, O'Neill J, et al. Health equity: evidence synthesis and knowledge translation methods. *Systematic Reviews*. 2013;2(1):43.
106. Baum F, Freeman T, Sanders D, Labonté R, Lawless A, Javanparast S. Comprehensive primary health care under neo-liberalism in Australia. *Social Science & Medicine*. 2016;168:43-52.
107. Taylor J, Blue I, Misan G. Approach to Sustainable Primary Health Care Service Delivery for Rural and Remote South Australia. *Australian Journal of Rural Health*. 2001;9(6):304-310.
108. Marmot M. Sir Michael Marmot, epidemiologist. In: Aedy R, editor. Sunday Profile. Radio National: ABC; 2012.
109. Mackean T. A healed and healthy country: understanding healing for Indigenous Australians. *Medical Journal of Australia*. 2009;190(10):522-523.
110. Zubrick SR, Dudgeon P, Gee G, et al. *Working together: Aboriginal Torres Strait Islander mental health wellbeing principles*. Australia Co; 2004.
111. Kingsley J, Munro-Harrison E, Jenkins A, Thorpe A. "Here we are part of a living culture": Understanding the cultural determinants of health in Aboriginal gathering places in Victoria, Australia. Article. *Health and Place*. 2018;54:210-220.
112. Paradies Y, Harris R, Anderson I. *The impact of racism on Indigenous health in Australia and Aotearoa: Towards a research agenda*. vol Discussion Paper No. 4. Cooperative Research Centre for Aboriginal Health; 2008.
113. Paradies Y. Colonisation, racism and Indigenous health. *Journal of Population Research*. 2016;33(1):83-96.
114. Larson A, Gillies M, Howard PJ, Coffin J. It's enough to make you sick: the impact of racism on the health of Aboriginal Australians. *Australian and New Zealand Journal of Public Health*. 2007;31(4):322-329.
115. Fogarty W, Lovell M, Langenberg J, Heron M-J. *Deficit Discourse and Strengths-based Approaches: Changing the Narrative of Aboriginal and Torres Strait Islander Health and Wellbeing*. The Lowitja Institute; 2018.
116. Milroy H. The Dance of Life. Online: The Royal Australian & New Zealand College of Psychiatrists; 2006.
117. Milroy H. The Dance of Life. The Royal Australian & New Zealand College of Psychiatrists. Accessed 5/12/2019, 2019. https://www.ranzcp.org/practice-education/indigenous-mental-health/aboriginal-torres-strait-islander-mental-health/the-dance-of-life
118. Behrendt L. *Achieving social justice: Indigenous rights and Australia's future*. Federation Press; 2003.
119. Daniel M, Lekkas P, Cargo M, Stankov I, Brown A. Environmental Risk Conditions and Pathways to Cardiometabolic Diseases in Indigenous Populations. *Annual Review of Public Health*. 2011;32(1):327-347.
120. Davy C, Kite E, Sivak L, et al. Towards the development of a wellbeing model for Aboriginal and Torres Strait Islander peoples living with chronic disease. Article. *BMC Health Services Research*. 2017;17(1)659.
121. Burgess CP, Johnston FH, Berry HL, et al. Healthy country, healthy people: the relationship between Indigenous health status and "caring for country". *Medical Journal of Australia*. 2009;190(10):567-572.
122. Lukaszyk C, Coombes J, Sherrington C, et al. The Ironbark program: Implementation and impact of a community‐based fall prevention pilot program for older Aboriginal and Torres Strait Islander people. *Health Promotion Journal of Australia*. 2018;29(2):189-198.

123. Dimer L, Dowling T, Jones J, et al. Build it and they will come: outcomes from a successful cardiac rehabilitation program at an Aboriginal Medical Service *Australian Health Review*. 2013;37(1):79-82.
124. Brown A, Scales U, Beever W, Rickards B, Rowley K, O'Dea K. Exploring the expression of depression and distress in Aboriginal men in central Australia: a qualitative study. *BMC Psychiatry*. 2012;12(1):97.
125. Australian Department o Health. *National Aboriginal and Torres Strait Islander Health Plan: 2013-2023*. 2013. 1742419798.
126. Anderson I, Baum F, Bentley M. *Beyond Bandaids: Exploring the Underlying Social Determinants of Aboriginal Health. Papers from the Social Determinants of Aboriginal Health Workshop, Adelaide, July 2004,*. 2007. *Proceedings of the Social Determinants of Aboriginal Health Workshop: July 2004; Darwin*.
127. Weir JK, Stacey C, Youngetob K. *The benefits associated with caring for country: literature review*. Department of Sustainability E, Water, Population and Communities,; 2011.
128. Dudgeon P, Milroy H, Walker R. *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice*. 2nd ed. Commonwealth of Australia; 2014.
129. Browne-Yung K, Ziersch A, Baum F, Gallaher G. Aboriginal Australians' experience of social capital and its relevance to health and wellbeing in urban settings. *Social Science & Medicine*. 2013;97:20-28.
130. Goldsmith S. Personal communication. Kaurna Land 2007.
131. Moreton-Robinson A. Whiteness, epistemology and Indigenous representation. *Whitening race: Essays in social and cultural criticism*. 2004;1:75-88.
132. Coombes J, Ryder C. Walking together to create harmony in research: A Murri woman's approach to Indigenous research methodology. *Qualitative Research in Organizations and Management*. 2019;ahead-of-print
133. UluruStatement. The Statement: Uluru Statment from the Heart. UluruStatement. Accessed 2/12/2019, 2020. https://ulurustatement.org/
134. Ryder C, Mackean T, Coombs J, et al. Indigenous research methodology – weaving a research interface. *International Journal of Social Research Methodology*. 2020;23(3):255-267.
135. Reynolds H. *Why weren't we told?: A personal search for the truth about our history*. Penguin Books; 2000.
136. Reynolds H. *The other side of the frontier: Aboriginal resistance to the European invasion of Australia*. UNSW Press; 2006.
137. Reynolds H. *Dispossession: Black Australians and white invaders*. Allen & Unwin Sydney; 1989.
138. Ryder C, Mackean T, Ullah S, et al. Development and Validation of a Questionnaire to Measure Attitude Change in Health Professionals after Completion of an Aboriginal Health and Cultural Safety Training Programme. *The Australian Journal of Indigenous Education*. 2017;48:1-15.
139. Australian Bureau of Statistics. *Census of Population and Housing: Reflecting Australia - Stories from the Census, 2016 Aboriginal and Torres Strait Islander population*. Australian Bureau of Statistics; 2016. Cat No 2071.0.
140. National Aboriginal Health Strategy Working Party. *A national Aboriginal health strategy*. NAHS Working Party; 1989.
141. Yap M, Yu E. Operationalising the capability approach: developing culturally relevant indicators of indigenous wellbeing – an Australian example. *Oxford Development Studies*. 2016;44(3):315-331.
142. Salmon M, Doery K, Dance P, et al. *Defining the Indefinable: Descriptors of Aboriginal and Torres Strait Islander Peoples' Cultures and their Links to Health and Wellbeing.* Australian National University; 2018.

143. Durey A, Thompson SC. Reducing the health disparities of Indigenous Australians: time to change focus. *BMC Health Services Research*. 2012;12(1):151.
144. Sherwood J. Colonisation–It's bad for your health: The context of Aboriginal health. *Contemporary Nurse*. 2013;46(1):28-40.
145. Walter M, Suina M. Indigenous data, Indigenous methodologies and Indigenous data sovereignty. *International Journal of Social Research Methodology*. 2019;22(3):233-243.
146. Humphery K. Dirty questions: Indigenous health and 'Western research'. *Australian and New Zealand Journal of Public Health*. 2001;25(3):197-202.
147. Paul D. *Casting Shadows and struggling for control: silence, resistance and negotiation in Australian Aboriginal Health*. The University of Western Australia 2007.
148. Marmot M. Why should the rich care about the health of the poor? *Canadian Medical Association Journal*. 2012;184(11):1231-1232.
149. Walter M. An economy of poverty. *Australian International Journal of Critical Indigenous Studies*. 2009;2(1):2-14.
150. Gee GC, Ford CL. Structural Racism and Health Inequities: Old Issues, New Directions. *Du Bois Review: Social Science Research on Race*. 2011;8(1):115-132.
151. Behrendt L, Larkin S, Griew R, Kelly P. *Review of higher education access and outcomes for Aboriginal and Torres Strait Islander people: Final Report*. Australian Government; 2012.
152. Australian Institute of Health Welfare. *Contribution of chronic disease to the gap in mortality between Aboriginal and Torres Strait Islander people and other Australians*. 2011.
153. Australian Institute of Health Welfare. *The health of Australia's prisoners 2018*. 2018.
154. Australian Institute of Health Welfare. *Aboriginal and Torres Strait Islander adolescent and youth health and wellbeing 2018*. 2018.
155. Jan S, Essue BM, Leeder SR. Falling through the cracks: the hidden economic burden of chronic illness and disability on Australian households. *The Medical Journal of Australia*. 2011;196(1):29-31.
156. Essue B, Kelly P, Roberts M, Leeder S, Jan S. We can't afford my chronic illness! The out-of-pocket burden associated with managing chronic obstructive pulmonary disease in western Sydney, Australia. *J Health Serv Res Policy*. 2011;16(4):226-31.
157. Essue BM, Beaton A, Hull C, et al. Living with economic hardship at the end of life. *BMJ Supportive and Palliative Care*. 2015;5(2):129-37.
158. Essue BM, Wong G, Chapman J, Li Q, Jan S. How are patients managing with the costs of care for chronic kidney disease in Australia? A cross-sectional study. *BMC Nephrology*. 2013;14(1):5.
159. Gatt L, Jan S, Mondraty N, et al. The household economic burden of eating disorders and adherence to treatment in Australia. *BMC Psychiatry*. 2014;14(1):338.
160. McRae I, Yen L, Jeon YH, Herath PM, Essue B. Multimorbidity is associated with higher out-of-pocket spending: A study of older Australians with multiple chronic conditions. Article. *Australian Journal of Primary Health*. 2013;19(2):144-149.
161. O'Neill KM, Mandigo M, Pyda J, et al. Out-of-pocket expenses incurred by patients obtaining free breast cancer care in Haiti: A pilot study. *Surgery*. 2015;158(3):747-55.
162. O'Donnell O, van Doorslaer, E., Wagstaff, A., & Lindelow, M. . Catastrophic payments for health care (Chap. 18) *Analyzing health equity using household survey data: A guide to techniques and their implementation* The World Bank; 2008. vol. WBI Learning Resources Series.
163. Pauly M, McGuire T, Barros P. *Handbook of Health Economics*. Elsevier; 2012.
164. Carpenter A, Islam MM, Yen L, McRae I. Affordability of out-of-pocket health care expenses among older Australians. *Health Policy*. 2015;119(7):907-914.
165. Organisation for Economic Co-operation and Development. *Health at a Glance 2015: OECD Indicators*. OECD Publishing; 2015.

166. The World Bank. Out-of-pocket health expenditure (% of private expenditure on health). The World Bank. Accessed 4/09/2017, https://data.worldbank.org/indicator/SH.XPD.OOPC.ZS
167. The Senate Community Affairs References Committee. *Out-of-pocket costs in Australian healthcare*. Commonewealth of Australia; 2014.
168. Jeon Y-H, Essue B, Jan S, Wells R, Whitworth JA. Economic hardship associated with managing chronic illness: a qualitative inquiry. *BMC Health Services Research*. 2009;9(1):182.
169. Callander E, Bates N, Lindsay D, et al. Long-term out of pocket expenditure of people with cancer: comparing health service cost and use for Indigenous and non-Indigenous people with cancer in Australia. *International Journal for Equity in Health*. 2019;18(1):32.
170. Cronin P, Reeve R, McCabe P, Viney R, Goodall S. The impact of childhood language difficulties on healthcare costs from 4 to 13 years: Australian longitudinal study. *Int J Speech Lang Pathol*. 2016:1-11.
171. Marmot M. Social determinants of health inequalities. *The Lancet*. 2005;365:1099-1104.
172. Foucault M. *The Birth of the Clinic: An Archaeology of Medical Perception*. Routledge; 2002.
173. Fox NJ. Health sociology from post-structuralism to the new materialisms. *Journal of Health*. 2016;20(1):62-74.
174. Rigney LI. A first perspective of Indigenous Australian participation in science: Framing Indigenous research towards Indigenous Australian intellectual sovereignty. *Kaurna Higher Education Journal*. 2001;7:1-13.
175. O'Brien L, Watson I. In conversation with Uncle Lewis: Bushfires, weather-makers, collective management. *AlterNative: An International Journal of Indigenous Peoples*. 2014;10(5):450-461.
176. Bessarab D. The supervisory yarn: Embedding Indigenous epistemology in supervision. *Our Voices: Aboriginal and Torres Strait Islander Social Work*. Palgrave-Macmillan; 2013:73-92.
177. Anderson V, Brown S, Newitt H, Hoile H. Educational, vocational, psychosocial, and quality-of-life outcomes for adult survivors of childhood traumatic brain injury. *The Journal of Head Trauma Rehabilitation*. 2009;24(5):303-312.
178. Shaw SR, McCabe PC. Hospital‐to‐school transition for children with chronic illness: Meeting the new challenges of an evolving health care system. *Psychology in the Schools*. 2008;45(1):74-87.
179. Kavanagh J, Oliver S, Lorenc T. Reflections on developing and using PROGRESS-Plus. *Equity Update*. 2008;2(1):1-3.
180. Covell K. United Nations Secretary-General's Study on Violence Against Children. North American Regional Consultation. Toronto: UNICEF Canada; 2005.
181. UNICEF. Convention on the Rights of the Child. https://www.unicef.org/crc/
182. Nasser M, Ueffing E, Welch V, Tugwell P. An equity lens can ensure an equity-oriented approach to agenda setting and priority setting of Cochrane Reviews. *Journal of Clinical Epidemiology*. 2013;66(5):511-521.
183. Williams D, Mohammed S. Discrimination and racial disparities in health: evidence and needed research. *Journal of Behavioral Medicine*. 2009;32(1):20-47.
184. Gahagan J, Gray K, Whynacht A. Sex and gender matter in health research: addressing health inequities in health research reporting. *International Journal for Equity in Health*. 2015;14(1):12.
185. Van Beeck EF, Larsen CF, Lyons RA, Meerding W-J, Mulder S, Essink-Bot M-L. Guidelines for the conduction of follow-up studies measuring injury-related disability. *Journal of Trauma and Acute Care Surgery*. 2007;62(2):534-550.

186. Lyons RA, Towner EE, Kendrick D, et al. The UK Burden of Injury Study–a protocol. *BMC Public Health*. 2007;7(1):317.
187. Waters E, de Silva - Sanigorski A, Burford BJ, et al. Interventions for preventing obesity in children. *The Cochrane Database Systematic Reviews*. 2011;CD001871(12)
188. Popay J, Roberts H, Sowden A, et al. *Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme*. Vol. Version 1. 2006:1-92.
189. Petticrew M, Roberts H. *Systematic Reviews in the Social Sciences: A Practical Guide*. Blackwell; 2006.
190. Viswanathan M, Berkman ND. Development of the RTI item bank on risk of bias and precision of observational studies. *Journal of Clinical Epidemiology*. Feb 2012;65(2):163-78.
191. McCarthy ML, MacKenzie EJ, Durbin DR, et al. Health-related quality of life during the first year after traumatic brain injury. *Archives of Pediatrics and Adolescent Medicine*. March 2006;160(3):252-260.
192. Jagnoor J, Prinja S, Christou A, Baker J, Gabbe B, Ivers R. Health-related quality of life and function after paediatric injuries in India: a longitudinal study. *International Journal of Environmental Research and Public Health*. 2017;14(10):1-12.
193. Yeates KO, Kaizar E, Rusin J, et al. Reliable change in postconcussive symptoms and its functional consequences among children with mild traumatic brain injury. *Archives of Pediatrics and Adolescent Medicine*. July 2012;166(7):615-622.
194. Moran LM, Taylor HG, Rusin J, et al. Quality of life in pediatric mild traumatic brain injury and its relationship to postconcussive symptoms. *Journal of Pediatric Psychology*. 2011;37(7):736-744.
195. Rotarescu V, Ciurea AV. Quality of life in children after mild head injury. *Journal of Medicine and Life*. 2008;1(3):307-22.
196. Ding R, McCarthy ML, Houseknecht E, et al. The health-related quality of life of children with an extremity fracture: a one-year follow-up study. *Journal of Pediatric Orthopaedics* Mar-Apr 2006;26(2):157-63.
197. Anderson V, Catroppa C, Dudgeon P, Morse SA, Haritou F, Rosenfeld J. Understanding predictors of functional recovery and outcome 30 months following early childhood head injury. *Neuropsychology*. 2006;20(1):42-57.
198. Sturms LM, van der Sluis CK, Stewart RE, Groothoff JW, Jan ten Duis H, Eisma WH. A prospective study on paediatric traffic injuries: Health-related quality of life and post-traumatic stress. *Clinical Rehabilitation*. May 2005;19(3):312-322.
199. Polinder S, Meerding WJ, Toet H, Mulder S, Essink-Bot ML, van Beeck EF. Prevalence and prognostic factors of disability after childhood injury. *Pediatrics*. 2005;116(6):e810-e817.
200. Yeates KO, Swift E, Taylor HG, et al. Short- and long-term social outcomes following pediatric traumatic brain injury. *Journal of the International Neuropsychological Society*. 2004;10(3):412-26.
201. Schwartz L, Taylor HG, Drotar D, Yeates KO, Wade SL, Stancin T. Long-term behavior problems following pediatric traumatic brain injury: prevalence, predictors, and correlates. *Journal of Pediatric Psychology*. 2003;28(4):251-63.
202. Stancin T, Drotar D, Taylor HG, Yeates KO, Wade SL, Minich NM. Health-related quality of life of children and adolescents after traumatic brain injury. *Pediatrics*. 2002;109(2):e34-e42.
203. Prasad MR, Ewing-Cobbs L, Swank PR, Kramer L. Predictors of outcome following traumatic brain injury in young children. *Pediatric Neurosurgery*. 2002;36(2):64-74.
204. Kumaraswamy N, Naziah A, Abdullah J, Ariff MAR, Abdullah MR, Ghazaime G. Outcome of children with traumatic brain injury in rural Malaysia. *Journal of Clinical Neuroscience*. 2002;9(3):251-5.

205. Anderson V, Catroppa C, Morse S, Haritou F, Rosenfeld J. Outcome from mild head injury in young children: a prospective study. *Journal of Clinical & Experimental Neuropsychology*. 2001;23(6):705-17.
206. Serghiou MH, Rose MW, Pidcock FS, et al. The WeeFIM [R] instrument--a paediatric measure of functional independence to predict longitudinal recovery of paediatric burn patients. *Developmental Neurorehabilitation*. 2008;11(1):39-50.
207. Disseldorp LM, Niemeijer AS, Van Baar ME, Reinders-Messelink HA, Mouton LJ, Nieuwenhuis MK. How disabling are pediatric burns? Functional independence in Dutch pediatric patients with burns. *Research in Developmental Disabilities* Jan 2013;34(1):29-39.
208. Palmieri TL, Nelson-Mooney K, Kagan RJ, et al. Impact of hand burns on health-related quality of life in children younger than 5 years. *The Journal of Trauma and Acute Care Surgery*. Sep 2012;73(3)(2):S197-S204.
209. Anderson V, Morse SA, Catroppa C, Haritou F, Rosenfeld J. Thirty month outcome from early childhood head injury: a prospective analysis of neurobehavioural recovery. *Brain*. 2004;127(12):2608-20.
210. Brown EA, Kenardy J, Chandler B, Anderson V, McKinlay L, Le Brocque R. Parent-Reported Health-Related Quality of Life in Children With Traumatic Brain Injury: A Prospective Study. *Journal of Pediatric Psychology*. 2016;41(2):244-55.
211. Catroppa C, Anderson VA, Morse SA, Haritou F, Rosenfeld JV. Outcome and predictors of functional recovery 5 years following pediatric traumatic brain injury (TBI). *Journal of Pediatric Psychology*. 2008;33(7):707-18.
212. Schneeberg A, Ishikawa T, Kruse S, et al. A longitudinal study on quality of life after injury in children. *Health and Quality of Life Outcomes* Aug 26 2016;14(1):120-131.
213. Stancin T, Kaugars AS, Thompson GH, et al. Child and family functioning 6 and 12 months after a serious pediatric fracture. *Journal of Trauma-Injury Infection & Critical Care*. 2001;51(1):69-76.
214. Anderson V, Godfrey C, Rosenfeld JV, Catroppa C. Predictors of cognitive function and recovery 10 years after traumatic brain injury in young children. *Pediatrics*. 2012;129(2):e254-e261.
215. Fewtrell MS, Kennedy K, Singhal A, et al. How much loss to follow-up is acceptable in long-term randomised trials and prospective studies? *Archives of Disease in Childhood*. 2008;93(6):458-461.
216. Kristman V, Manno M, Côté P. Loss to follow-up in cohort studies: how much is too much? *European Journal of Epidemiology*. 2004;19(8):751-760.
217. Atlantic Collaborative of Injury Prevention. *The Social Determinants of Injury*. Atlantic Collaborative on Injury Prevention 2011:1-56.
218. National Health and Medical Research Council. *Values and ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research*. Commonwealth of Australia; 2003. https://www.nhmrc.gov.au/
219. Alexandrescu R, O'Brien SJ, Lecky FE. A review of injury epidemiology in the UK and Europe: some methodological considerations in constructing rates. *BMC Public Health*. 2009;9(1):226.
220. Petridou E, Anastasiou A, Katsiardanis K, Dessypris N, Spyridopoulos T, Trichopoulos D. A prospective population based study of childhood injuries: the Velestino town study. *The European Journal of Public Health*. 2005;15(1):9-14.
221. Pomerantz WJ, Dowd MD, Buncher CR. Relationship between socioeconomic factors and severe childhood injuries. *Journal of Urban Health*. 2001;78(1):141-151.
222. Faelker T, Pickett W, Brison RJ. Socioeconomic differences in childhood injury: a population based epidemiologic study in Ontario, Canada. *Injury Prevention*. 2000;6(3):203-208.

223. Chapman EN, Kaatz A, Carnes M. Physicians and implicit bias: how doctors may unwittingly perpetuate health care disparities. *Journal of General Internal Medicine*. 2013;28(11):1504-1510.
224. Ruiz-Cantero MT, Vives-Cases C, Artazcoz L, et al. A framework to analyse gender bias in epidemiological research. *Journal of Epidemiology & Community Health*. 2007;61(2):ii46-ii53.
225. Williams AS, Moore SM. Universal Design of Research: Inclusion of Persons with Disabilities in Mainstream Biomedical Studies. *Science Translational Medicine*. 2011;3(82):1-10.
226. McDonagh M, Peterson K, Raina P, Chang S, Shekelle P. *Avoiding Bias in Selecting Studies*. Agency for Healthcare Research and Quality; 2013.
227. Cochrane. *Reporting Biases*. Cochrane Methods Bias; 2018. https://methods.cochrane.org/bias/reporting-biases
228. Foucault M. *Politics, philosophy, culture: Interviews and other writings, 1977-1984*. Routledge; 1988.
229. McHoul A, Grace W. *A Foucault primer: Discourse, power and the subject*. Melbourne University Press; 1993.
230. Martin KMB. Ways of knowing, being and doing: A theoretical framework and methods for indigenous and indigenist re‐search. *Journal of Australian Studies*. 2003;27(76):203-214.
231. Winter G. A comparative discussion of the notion of 'validity' in qualitative and quantitative research. *The Qualitative Report*. 2000;4(3):1-14.
232. Taylor D. *Michel Foucault : key concepts*. Durham : Acumen; 2014.
233. McNay L. *Foucault and Feminism: Power, Gender and the Self*. Blackwell Publishers; 1992.
234. Langton M, Rhea ZM. Traditional Indigenous biodiversity-related knowledge. *Australian Academic & Research Libraries*. 2005;36(2):45-69.
235. Whap G. A Torres Strait Islander perspective on the concept of indigenous knowledge. *The Australian Journal of Indigenous Education*. 2001;29(2):22-29.
236. Louis RP. Can you hear us now? Voices from the margin: Using indigenous methodologies in geographic research. *Geographical research*. 2007;45(2):130-139.
237. Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council. *Ngangkari Work-Anangu Way. Traditional Healers of Central Australia*. NPY Women's Council Aboriginal Corporation; 2003.
238. Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council. *Aboriginal Corporation: Working together, Traditional Healers of Central Australia: Ngangkari*. Broome WA: Magabala books. Council, Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's; 2013:239-245.
239. Roberts A, Mollenmans A, Agius Q, et al. "They planned their calendar… they set up ready for what they wanted to feed the tribe": a first-stage analysis of Narungga fish traps on Yorke Peninsula, South Australia. *The Journal of Island and Coastal Archaeology*. 2016;11(1):1-25.
240. Jordan J. The engineering of Budj Bim and the evolution of a societal structure in Aboriginal Australia. *Australian Journal of Multi-Disciplinary Engineering*. 2012;9(1):63-68.
241. Ross PJ. *Ngarrindjeri Fish Traps of the Lower Murray Lakes and Norther Coorong Estuary, South Australia*. Flinders University; 2009.
242. Rowland MJ, Ulm S. Indigenous fish traps and weirs of Queensland. *Queensland Archaeological Research*. 2011;14:1-58.
243. Lumley K. Learning about Aboriginal astronomy. *Judicial Officers Bulletin*. 2018;30(5):47.
244. Aboriginal sovereignty—never ceded. *Australian Historical Studies*. 1988;23(91):1-2.
245. Singh M, Major J. Conducting Indigenous research in Western knowledge spaces: aligning theory and methodology. *The Australian Educational Researcher*. 2017;44(1):5-19.

246. Davis JA. *Durithunga: Growing, nurturing, challenging and supporting urban Indigenous leadership in education*. Queensland University of Technology; 2018.
247. Kickett M. *Examination of how a culturally-appropriate definition of resilience affects the physical and mental health of Aboriginal People*. University of Western Australia; 2012.
248. Toombs M. *What factors do Aboriginal and Torres Strait Islander students say affect their social and emotional wellbeing while at University?* University of Southern Queensland; 2011.
249. Bond CJ. *" When you're black, they look at you harder" Narrating Aboriginality within Public Health*. University of Queensland; 2007.
250. Martin K. *Please knock before you enter: an investigation of how rainforest Aboriginal people regulate outsiders and the implications for western research and researchers*. James Cook University; 2006.
251. Dudgeon P, Walker R. Decolonising Australian psychology: Discourses, strategies, and practice. *Journal of Social and Political Psychology*. 2015;3(1):276-297.
252. Rigney LI. Internationalization of an Indigenous anticolonial cultural critique of research methodologies: A guide to Indigenist research methodology and its principles. *Journal for Native American Studies*. 1999;14(2):109-121.
253. Doyle K, Cleary M, Blanchard D, Hungerford C. The Yerin Dilly Bag Model of Indigenist Health Research. *Qualitative Health Research*. 2017;27(9):1288-1301.
254. Tur SU, Blanch FR, Wilson C. Developing a collaborative approach to standpoint in Indigenous Australian research. *The Australian Journal of Indigenous Education*. 2010;39(S1):58-67.
255. Saunders V, West R, Usher K. Applying Indigenist research methodologies in health research: Experiences in the borderlands. *Australian Journal of Indigenous Education*. 2010;39(S1):1-7.
256. Nakata M. The cultural interface. *The Australian Journal of Indigenous Education*. 2007;36(S1):7-14.
257. Nakata M. The Cultural Interface of Islander and Scientific Knowledge. *The Australian Journal of Indigenous Education*. 2010;39(S1):53-57.
258. Henry J, Dunbar T, Arnott A, et al. *Indigenous Research Reform Agenda. Rethinking Research Methodologies*. Cooperative Research Centre for Aboriginal and Tropical Health; 2002. *Series 2*. Series 2.
259. Smith L. *Decolonizing methodologies: Research and Indigenous peoples*. Zed books; 1999.
260. Durie M. Indigenous knowledge within a global knowledge system. *Higher Education Policy*. 2005;18(3):301-312.
261. Durie M. Understanding health and illness: research at the interface between science and Indigenous knowledge. *International Journal of Epidemiology*. 2004;33(5):1138-1143.
262. Absolon (Minogiizhigokwe) KE. *Kaandosswin: How we come to know*. Fernwood Publishing; 2011.
263. Council R. Uluru Statement from the Heart: Statement of the First Nations National Constitutional Convention. Referendum Council. July 2018, Updated May 26th 2017. Accessed July 2018, https://antar.org.au/statement-from-the-heart
264. Wilson A, Kelly J, Magarey A, Jones M, Mackean T. Working at the interface in Aboriginal and Torres Strait Islander health: focussing on the individual health professional and their organisation as a means to address health equity. *International Journal for Equity in Health*. 2016;15(1):1-12.
265. Bartlett C, Marshall M, Marshall A. Two-eyed seeing and other lessons learned within a co-learning journey of bringing together Indigenous and mainstream knowledges and ways of knowing. *Journal of Environmental Studies and Sciences*. 2012;2(4):331-340.

266. Antoine D. Pushing the Academy: The Need for Decolonizing Research. *Canadian Journal of Communication*. 2017;42(1):113.
267. Bhabha HK. Democracy De-realized. *Diogenes*. 2003;50(1):27-35.
268. Willis E, Dwyer J, Kelly J, Mackean T. Hybrid cultures: creating a third space in Aboriginal Healthcare. *Journal of Australian Indigenous Issues*. 2015;18(4):2-20.
269. Bhabha HK. *Our neighbours, ourselves: Contemporary reflections on survival*. Walter de Gruyter; 2011.
270. Laycock A, Walker D, Harrison N, Brands J. *Researching Indigenous health: a practical guide for researchers*. Lowitja Institute; 2011.
271. O'Donnell K, Kelly J. Using Ganma knowledge sharing as a decolonising approach to conference planning and facilitation. *ALAR: Action Learning and Action Research Journal*. 2011;17(2):137.
272. Worby G, Rigney L-I, Tur SU. Where salt and fresh waters meet: reconciliation and change in education. *Australian Cultural History*. 2010;28(2-3):201-224.
273. Williams W. Personal Communication on Learning and Research at the Interface. In: Ryder C, editor. Aboriginal Health Education 2018.
274. Wylie A. Why standpoint matters. In: Figueroa R, Harding S, eds. *Science and Other Cultures: Issues in Philosophies of Science and Technology*. Routledge; 2013:34-56.
275. Moreton-Robinson A. Towards an Australian Indigenous Women's Standpoint Theory. *Australian Feminist Studies*. 2013;28(78):331-347.
276. Bell D. *Ngarrindjeri Wurruwarrin: A world that is, was, and will be*. Spinifex Press; 1998.
277. Carmichael EJ. *How is weaving past, present, futures?* Queensland University of Technology; 2017.
278. Garwood-Houng A. *Baskets Hold a History: Yorta Yorta Basket Making*. Australian National University; 2015.
279. Green S, Bennett B. Wayanha: A Decolonised Social Work. *Australian Social Work*. 2018;71(3):261-264.
280. Jones JK. *Weaving words: personal and professional transformation through writing as research*. Cambridge Scholars Publishing; 2014.
281. Gale M-A, McHughes E, Williams P, Koolmatrie V. Lakun Ngarrindjeri thunggari: Weaving the Ngarrindjeri language back to health. *Australian Aboriginal Studies*. 2012;(2):42.
282. Wilson A. Addressing uncomfortable issues: reflexivity as a tool for culturally safe practice in Aboriginal and Torres Strait Islander health. *The Australian Journal of Indigenous Education*. 2014;43(2):218-230.
283. AIHW. *The health and welfare of Australia's Aboriginal and Torres Strait Islander people, an overview 2011* Vol. Cat. no. IHW 42 2011.
284. Möller H, Falster K, Ivers R, Clapham K, Harvey L, Jorm L. High rates of hospitalised burn injury in Indigenous children living in remote areas: a population data linkage study. *Australian and New Zealand Journal of Public Health*. 2017;
285. Sherwood J, Edwards T. Decolonisation: A critical step for improving Aboriginal health. *Contemporary Nurse*. 2006;22(2):178-190.
286. McHugh ML. The chi-square test of independence. *Biochemia medica: Biochemia medica*. 2013;23(2):143-149.
287. MacDonald TH, Gray DP. *Basic concepts in statistics and epidemiology*. CRC Press; 2016.
288. Smith LT. *Decolonizing Methodologies : Research and Indigenous Peoples*. vol 2nd ed. Zed Books; 2012.
289. Sheehan N, Walker P. The Purga project: Indigenous knowledge research. *The Australian Journal of Indigenous Education*. 2001;29(2):11-17.

290. Möller H, Falster K, Ivers R, et al. Inequalities in hospitalized unintentional injury between Aboriginal and non-Aboriginal children in New South Wales, Australia. *American Journal of Public Health*. 2016;
291. West R, Stewart L, Foster K, Usher K. Through a critical lens: Indigenist research and the Dadirri method. *Qualitative Health Research*. 2012;22(11):1582-1590.
292. Walker M, Fredericks B, Mills K, Anderson D. "Yarning" as a method for community-based health research with indigenous women: the Indigenous women's wellness research program. *Health Care for Women International*. 2014;35(10):1216-1226.
293. Geia LK, Hayes B, Usher K. Yarning/Aboriginal storytelling: towards an understanding of an Indigenous perspective and its implications for research practice. *Contemporary Nurse*. 2013;46(1):13-17.
294. Leeson S, Smith C, Rynne J. Yarning and appreciative inquiry: The use of culturally appropriate and respectful research methods when working with Aboriginal and Torres Strait Islander women in Australian prisons. *Methodological Innovations*. 2016;9:1-17.
295. Baker J. *Theorising survival: Indigenous women and social and emotional wellbeing*. Post Pressed; 2012.
296. Heddle NM. Clinical research designs: Quantitative studies. *Vox sanguinis*. 2002;83:247-250.
297. Weaver A, Goldberg S. *Clinical biostatistics and epidemiology made ridiculously simple*. MedMaster; 2012.
298. Kwak C, Clayton-Matthews A. Multinomial logistic regression. 2002;51(6):404-410.
299. StataCorp. *Stata Multiple-Imputation Reference Manual Release 15*. 15 ed. Stata Press; 2017.
300. Anthoine E, Moret L, Regnault A, Sébille V, Hardouin J-B. Sample size used to validate a scale: a review of publications on newly-developed patient reported outcomes measures. *Health and Quality of Life Outcomes*. 2014;12:2.
301. Polit DF, Beck CT, Owen SV. Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Research in Nursing and Health*. 2007;30(4):459-467.
302. Lynn MR. Determination and quantification of content validity. *Nursing research*. 1986;35(6):382-386.
303. Marsden PV, Wright JD. *Handbook of Survey Research*. Emerald; 2010.
304. Fabrigar LR, Wegener DT. *Exploratory factor analysis*. Oxford University Press; 2011.
305. Yong AG, Pearce S. A beginner's guide to factor analysis: Focusing on exploratory factor analysis. *Tutorials in Quantitative Methods for Psychology*. 2013;9(2):79-94.
306. Gliem JA, Gliem RR. Calculating, interpreting, and reporting Cronbach's alpha reliability coefficient for Likert-type scales. Midwest Research-to-Practice Conference in Adult, Continuing, and Community Education; 2003:
307. Bravo G, Potvin L. Estimating the reliability of continuous measures with Cronbach's alpha or the intraclass correlation coefficient: toward the integration of two traditions. *Journal of Clinical Epidemiology*. 1991;44(4):381-390.
308. van Baar ME, Essink-Bot ML, Oen I, et al. Reliability and validity of the Dutch version of the American Burn Association/Shriners Hospital for Children Burn Outcomes Questionnaire (5-18 years of age). *Journal of Burn Care and Research*. 2006;27(6):790-802.
309. Waddell C, Dibley M. The medicalization of Aboriginal children: A comparison of the lengths of hospital‐stay of Aboriginal and non‐Aboriginal children in Western Australia and the Northern Territory. *Journal of Paediatrics and Child Health*. 1986;22(1):27-30.
310. United Nations. *United Nations Declaration on the Rights of Indigenous Peoples*. United Nations; 2007
311. Sherwood J. *Do no harm: decolonising Aboriginal health research*. University of New South Wales; 2010.

312. Department of Social Services. *Longitudinal Study of Indigenous Children – Key Summary Report from Wave 4*. 2013. https://www.dss.gov.au/
313. Department of Social Services. *Longitudinal Study of Indigenous Children – Key Summary Report from Wave 3*. 2012. https://www.dss.gov.au/
314. Alnababtah K, Khan S, Ashford R. Socio-demographic factors and the prevalence of burns in children: an overview of the literature. *Paediatrics International Child Health*. 2016;36(1):45-51.
315. Armstrong M, Wheeler KK, Shi J, et al. Epidemiology and trend of US pediatric burn hospitalizations, 2003–2016. *Burns*. 2020;
316. Edelman LS. Social and economic factors associated with the risk of burn injury. *Burns*. 2007;33(8):958-65.
317. Banerji A. Preventing unintentional injuries in Indigenous children and youth in Canada. *Paediatrics and Child Health*. 2012;17(7):393.
318. Alaghehbandan R, Sikdar KC, MacDonald D, Collins KD, Rossignol AM. Unintentional injuries among children and adolescents in Aboriginal and non-Aboriginal communities, Newfoundland and Labrador, Canada. *International Journal of Circumpolar Health*. 2010;69(1):61-71.
319. Berger LR, Wallace LJD, Bill NM. Injuries and Injury Prevention Among Indigenous Children and Young People. Review. *Pediatric Clinics of North America*. 2009;56(6):1519-1537.
320. Harrop AR, Brant RF, Ghali WA, Macarthur C. Injury mortality rates in Native and non-Native children: a population-based study. *Public Health Rep*. May-Jun 2007;122(3):339-346.
321. Edelman LS, Cook LJ, Saffle JR. Burn injury in Utah: Demographic and geographic risks. Article. *Journal of Burn Care and Research*. 2010;31(3):375-384.
322. Bai W, Specker B. Racial Differences in Hospitalizations Due to Injuries in South Dakota Children and Adolescents. Article. *Journal of Racial and Ethnic Health Disparities*. 2019;6(6):1087-1094.
323. Bell NJ, Schuurman N, Hameed SM. A small-area population analysis of socioeconomic status and incidence of severe burn/fire-related injury in British Columbia, Canada. *Burns*. 2009;35(8):1133-1141.
324. Stockton K, Harvey J, Kimble R. A prospective observational study investigating all children presenting to a specialty paediatric burns centre. *Burns*. 2015;41(3):476-483.
325. Gabbe BJ, Watterson DM, Singer Y, Darton A. Outpatient presentations to burn centers: data from the Burns Registry of Australia and New Zealand outpatient pilot project. *Burns*. 2015;41(3):446-453.
326. Cassidy TJ, Edgar DW, Phillips M, Cameron P, Cleland H, Wood FM. Transfer time to a specialist burn service and influence on burn mortality in Australia and New Zealand: A multi-centre, hospital based retrospective cohort study. *Burns*. 2015;41(4):735-741.
327. Vetrichevvel TP, Randall SM, Wood FM, Rea S, Boyd JH, Duke JM. A population-based comparison study of the mental health of patients with intentional and unintentional burns. *Burns and Trauma*. 2018;6(1):31.
328. Wood FM, Fowler BV, McAullay D, Jones JR. Major burns: incidence, treatment and outcomes in Aboriginal and non-Aboriginal people in Western Australia. *Medical Journal of Australia*. 2005;182(3):138.
329. Hacking I. Making Up People. In: Heller T, Sosna M, Wellbery D, eds. *Reconstructing Individualism*. Stanford University Press; 1985.
330. Kukutai T, Taylor J. *Indigenous Data Sovereignty: Toward an Agenda*. ANU Press; 2016:79-98.
331. BRANZ. *Burns Registry of Australia and New Zealand Data Dictionary*. vol 2.0. Monash University; 2018.
332. Australian Bureau of Statistics. Socio-economic Indexes for Areas (SEIFA). data cube: excel spreadsheet. Table 1 http://www.abs.gov.au/

333. Australian Bureau of Statistics. Postcode 2012 to Remoteness Area 2011. data cube: Excel spreadsheet. Table 3 cat. no. 1270.0.55.006. http://www.abs.gov.au/
334. Australia_Post. Standard Postcode File. Australia Post. Accessed 15th November 2017, https://postcode.auspost.com.au/
335. National Centre for Classification in Health. *The International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian Modification (ICD-10-AM)*. 10th Edition ed. National Centre for Classification in Health, University of Sydney; 2008.
336. Morris TP, White IR, Royston P. Tuning multiple imputation by predictive mean matching and local residual draws. *BMC Medical Research Methodology*. 2014;14(1):75.
337. ggplot2: Elegant Graphics for Data Analysis. Wickam H. 2016.
338. Australian Bureau of Statistics. Data from: Australian Bureau of Statistics 2016 - Census Data Tablebuilder. 2016 *Canberra*.
339. Australian Institute of Health and Welfare. *Australia's Health 2018*. Australian Institute of Health and Welfare; 2018. Cat. No. AUS 221; Australia's Health Series No. 16.
340. Mistry R, Pasisi L, Chong S, Stewart J, She RWJB. Socioeconomic deprivation and burns. 2010;36(3):403-408.
341. Kramer CB, Rivara FP, Klein MB. Variations in U.S. pediatric burn injury hospitalizations using the national burn repository data. Article. *Journal of Burn Care and Research*. 2010;31(5):734-739.
342. Klein E. Settler colonialism in Australia and the cashless debit card. 2020;54(2):265-277.
343. Swann JA, Matthews MR, Bay C, Foster KN. Burn injury outcome differences in Native Americans. Article. *Burns*. 2019;45(2):494-501.
344. Duke J, Rea S, Semmens J, Wood F. Urban compared with rural and remote burn hospitalisations in Western Australia. *Burns*. 2012;38(4):591-598.
345. Ryan C, Shankowsky H, Tredget E. Profile of the paediatric burn patient in a Canadian burn centre. *Burns*. 1992;18(4):267-272.
346. Cass A, Cunningham J, Snelling P, Wang Z, Hoy W. Exploring the pathways leading from disadvantage to end-stage renal disease for Indigenous Australians. *Journal of Social Science Medicine*. 2004;58(4):767-785.
347. Dowler J, Wilson A. Acute post-streptococcal glomerulonephritis in Central Australia. Article. *Australian Journal of Rural Health*. 2019;
348. Davidson L, Knight J, Bowen AC. Skin infections in Australian Aboriginal children: a narrative review. Review. *Medical Journal of Australia*. 2020;212(5):231-237.
349. Hoy WE, White AV, Dowling A, et al. Post-streptococcal glomerulonephritis is a strong risk factor for chronic kidney disease in later life. *Kidney International*. 2012;81(10):1026-1032.
350. Chaturvedi S, Boyd R, Krause V. Acute post-streptococcal glomerulonephritis in the northern territory of Australia: a review of data from 2009 to 2016 and comparison with the literature. *The American journal of tropical medicine hygiene*. 2018;99(6):1643-1648.
351. Fraser S, Grant J, Mackean T, et al. What informs care? Descriptions by multidisciplinary teams about burns care for Aboriginal and Torres Strait Islander children. *Burns*. 2019;46(2):430-440.
352. Fraser S, Grant J, Mackean T, et al. Burn injury models of care: A review of quality and cultural safety for care of Indigenous children. *Burns*. 2018;44(3):665-677.
353. Dummer TJB. How should we act on the social determinants of health? *Canadian Medical Association Journal*. 2018;190(42)
354. Randall DA, Lujic S, Leyland AH, Jorm LR. Statistical methods to enhance reporting of Aboriginal Australians in routine hospital records using data linkage affect estimates of health disparities. *Australian and New Zealand Journal of Public Health*. 2013;37(5):442-449.
355. Salmon M, Skelton F, Thurber KA, et al. Intergenerational and early life influences on the well-being of Australian Aboriginal and Torres Strait Islander children: overview and

selected findings from Footprints in Time, the Longitudinal Study of Indigenous Children. *Journal of Developmental Origins of Health and Disease*. 2019;10(1):17-23.
356. Kornhaber R, Rickard G, McLean L, Wiechula R, Lopez V, Cleary M. Burn care and rehabilitation in Australia: health professionals' perspectives. *Disability and Rehabilitation*. 2017;41(6):1-6.
357. Dolp R, Rehou S, McCann MR, Jeschke MG. Contributors to the length-of-stay trajectory in burn-injured patients. Article. *Burns*. 2018;44(8):2011-2017.
358. Moore L, Cisse B, Kuimi BLB, et al. Impact of socio-economic status on hospital length of stay following injury: a multicenter cohort study. *BMC health services research*. 2015;15(285):1-9.
359. Hussain A, Dunn KW. Predicting length of stay in thermal burns: a systematic review of prognostic factors. *Burns*. Nov 2013;39(7):1331-40.
360. AbdelWahab ME, Sadaka MS, Elbana EA, Hendy AA. Evaluation of prognostic factors affecting length of stay in hospital and mortality rates in acute burn patients. Article. *Annals of Burns and Fire Disasters*. 2018;31(2):83-88.
361. Taylor SL, Sen S, Greenhalgh DG, Lawless M, Curri T, Palmieri TL. Not all patients meet the 1 day per percent burn rule: A simple method for predicting hospital length of stay in patients with burn. Article. *Burns*. 2017;43(2):282-289.
362. Gravante G, Delogu D, Esposito G, Montone A. Analysis of prognostic indexes and other parameters to predict the length of hospitalization in thermally burned patients. *Burns*. May 2007;33(3):312-5.
363. Sierra Zúñiga MF, Castro Delgado OE, Merchán-Galvis AM, Caicedo JCC, Calvache JA, Delgado-Noguera M. Factors associated with length of hospital stay in minor and moderate burns at Popayan, Colombia. Analysis of a cohort study. Article. *Burns*. 2016;42(1):190-195.
364. Humphreys JS. Key considerations in delivering appropriate and accessible health care for rural and remote populations: discussant overview. *Australian Journal of Rural Health*. 2009;17(1):34-38.
365. Wakerman J, Humphreys JS, Wells R, Kuipers P, Entwistle P, Jones J. Primary health care delivery models in rural and remote Australia – a systematic review. *BMC Health Services Research*. 2008;8(1):276.
366. Russell DJ, Wakerman J, Humphreys JS. What is a reasonable length of employment for health workers in Australian rural and remote primary healthcare services? *Australian Health Review*. 2013;37(2):256-261.
367. Harish V, Li Z, Maitz PKM. The optimal timing of outpatient Biobrane™ application for superficial and mid dermal partial thickness burns: Evidence for the '12-hour rule'. *Burns*. 2019;45(4):936-941.
368. Greenwood JE, Clausen J, Kavanagh S. Experience with biobrane: uses and caveats for success. *Eplasty*. 2009;9:e25-e25.
369. Lee C, Hanly M, Larter N, Zwi K, Woolfenden S, Jorm L. Demographic and clinical characteristics of hospitalised unintentional poisoning in Aboriginal and non-Aboriginal preschool children in New South Wales, Australia: a population data linkage study. *BMJ Open*. 2019;9(1):e022633-e022633.
370. Indigenous Allied Health Association. *Cultural Responsiveness In Action: An IAHA Framework*. Indigenous Allied Health Australia; 2015.
371. Shahid S, Durey A, Bessarab D, Aoun SM, Thompson SC. Identifying barriers and improving communication between cancer service providers and Aboriginal patients and their families: the perspective of service providers. *BMC Health Services Research*. 2013;13(1):460.
372. Sherwood J. Who is Not Coping with Colonization? Laying Out the Map for Decolonization. *Australasian Psychiatry*. 2009;17(1_suppl):S24-S27.
373. Alonso Y. The biopsychosocial model in medical research: the evolution of the health concept over the last two decades. *Patient Education and Counseling*. 2004;53(2):239-244.

374. Baum F. *The New Public Health*. Fourth ed. Oxford University Press; 2016.
375. Priest N, Mackean, T., Davis, E., Briggs, L. Waters, E. Aboriginal perspectives of child health and wellbeing in an urban setting: Developing a conceptual framework. *Health Sociology Review*. 2012;21(2):180-195.
376. Purdie N, Dudgeon P, Walker R. *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice*. Telethon Institute for Child Health Research/Kulunga Research Network; 2012. 2nd Edition.
377. Zubrick SR, Lawrence DM, Silburn SR, et al. *The Western Australian Aboriginal Child Health Survey: The Health of Aboriginal Children and Young People*. Telethon Institute for Child Health Research; 2004.
378. Callander EJ, Fox H, Lindsay D. Out-of-pocket healthcare expenditure in Australia: trends, inequalities and the impact on household living standards in a high-income country with a universal health care system. *Health Economics Review*. 2019;9(1):10.
379. Hynd A, Roughead EE, Preen DB, Glover J, Bulsara M, Semmens J. The impact of co‐payment increases on dispensings of government‐subsidised medicines in Australia. *Pharmacoepidemiology Drug Safety*. 2008;17(11):1091-1099.
380. Couzos S, Murray RM. *Aboriginal Primary Health Care*. 3rd ed. Oxford University Press; 2008.
381. Couzos S. PBS medications: Improving access for Aboriginal and Torres Strait Islander peoples. Article. *Australian Family Physician*. 2005;34(10):841-844.
382. Durey A, Wynaden D, Thompson SC, Davidson PM, Bessarab D, Katzenellenbogen JM. Owning solutions: a collaborative model to improve quality in hospital care for Aboriginal Australians. *Nursing inquiry*. 2012;19(2):144-152.
383. Australian Consortium for Classification Development. *The international statistical classification of diseases and related health problems, tenth revision, Australian modification (ICD-10-AM/ACHI/ACS)*. vol Tenth Edition. Independent Hospital Pricing Authority; 2017
384. Rentoul RR. Midwives Bills Opposition Expenses. *British Medical Journal*. 1896;1(1838):759-759.
385. Xu K, Evans DB, Carrin G, Aguilar-Rivera AM, Musgrove P, Evans T. Protecting households from catastrophic health spending. *Health affairs*. 2007;26(4):972-983.
386. Callander EJ, Corscadden L, Levesque J-F. Out-of-pocket healthcare expenditure and chronic disease – do Australians forgo care because of the cost? *Australian Journal of Primary Health*. 2017;23(1):15-22.
387. Yusuf F, Leeder S. Recent estimates of the out-of-pocket expenditure on health care in Australia. Article. *Australian Health Review*. 2020;44(3):340-346.
388. Walter M. Social exclusion/inclusion for urban Aboriginal and Torres Strait Islander people. *Social Inclusion*. 2016;4(1)
389. Siffleet J, Munns A, Shields L. Costs of meals and parking for parents of hospitalised children in an Australian paediatric hospital. *Neonatal, Paediatric and Child Health Nursing*. 2010;13(3):7-11.
390. Mumford V, Baysari MT, Kalinin D, et al. Measuring the financial and productivity burden of paediatric hospitalisation on the wider family network. *Journal of Paediatrics Child Health*. 2018;54(9):987-996.
391. Sluys KP, Lannge M, Iselius L, Eriksson LE. Six years beyond pediatric trauma: child and parental ratings of children's health-related quality of life in relation to parental mental health. Research Support, Non-U.S. Gov't. *Quality of Life Research*. 2015;24(11):2689-99.
392. McGrath P. 'The bills that were coming in…': out of pocket costs during relocation for specialist treatment for haematological malignancies. Article. *Supportive Care in Cancer*. 2016;24(7):2893-2903.

393. 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 *Australian Health Review*. 2011;35(2):235-241.
394. Thompson S, Shahid S, Greville H, 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*. Cancer Council Western Australia; 2011.
395. Dunbar T. Aboriginal People's experiences of health and family services in the Northern Territory. *International Journal of Critical Indigenous Studies*. 2011;4(2):2-16.
396. Kite E, Davy C. Using Indigenist and Indigenous methodologies to connect to deeper understandings of Aboriginal and Torres Strait Islander peoples' quality of life. *Health Promotion Journal of Australia*. 2015;26(3):191-4.
397. Murray R. Prescribing issues for Aboriginal people. *Australian Prescribing*. 2003;26:106-109.
398. Schoen C, Osborn R, Squires D, Doty M, Pierson R, Applebaum S. How Health Insurance Design Affects Access To Care And Costs, By Income, In Eleven Countries. *Health Affairs*. 2010;29(12):2323-2334.
399. Le Grande M, Ski C, Thompson D, et al. Social and emotional wellbeing assessment instruments for use with Indigenous Australians: A critical review. *Social Science and Medicine*. 2017;187:164-173.
400. Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*. 2018;18(1):143.
401. Paul C, Bonevski B, Twyman L, et al. The 'price signal' for health care is loud and clear: A cross-sectional study of self-reported access to health care by disadvantaged Australians. Research Support, Non-U.S. Gov't. *Australian and New Zealand Journal of Public Health*. 2016;40(2):132-7.
402. Gordon L, Scuffham P, Hayes S, Newman B. Exploring the economic impact of breast cancers during the 18 months following diagnosis. *Psycho-Oncology*. 2007;16(12):1130-1139.
403. Kirby ER, Broom AF, Sibbritt DW, Refshauge KM, Adams J. Health care utilisation and out-of-pocket expenditure associated with back pain: a nationally representative survey of Australian women. Research Support, Non-U.S. Gov't. *PLoS ONE*. 2013;8(12):e83559.
404. Mofizul Islam M, Yen L, Valderas JM, McRae IS. Out-of-pocket expenditure by Australian seniors with chronic disease: The effect of specific diseases and morbidity clusters. Article. *BMC Public Health*. 2014;14(1)1008.
405. Koo TK, Li MY. A guideline of selecting and reporting intraclass correlation coefficients for reliability research. *Journal of Chiropractic Medicine*. 2016;15(2):155-163.
406. Shrout PE, Fleiss JL. Intraclass correlations: uses in assessing rater reliability. *Psychological Bulletin*. 1979;86(2):420.
407. McGraw KO, Wong SP. Forming inferences about some intraclass correlation coefficients. *Psychological Methods*. 1996;1(1):30.
408. Thabane L, Ma J, Chu R, et al. A tutorial on pilot studies: the what, why and how. *BMC Medical Research Methodology*. 2010;10(1):1.
409. Hertzog MA. Considerations in determining sample size for pilot studies. *Research in Nursing and Health*. 2008;31(2):180-191.
410. Connelly LM. Pilot studies. *MEDSURG Nursing*. 2008;17(6):411.
411. Lancaster GA, Dodd S, Williamson PR. Design and analysis of pilot studies: recommendations for good practice. *Journal of Evaluation in Clinical Practice*. 2004;10(2):307-312.
412. Williams B, Onsman A, Brown T. Exploratory factor analysis: A five-step guide for novices. *Australasian Journal of Paramedicine*. 2010;8(3):1-14.

413. Watkins MW. Exploratory Factor Analysis: A Guide to Best Practice. *Journal of Black Psychology*. 2018;44(3):219-246.
414. Osborne JW, Costello AB. Best practices in exploratory factor analysis: Four recommendations for getting the most from your analysis. *Pan-Pacific Management Review*. 2009;12(2):131-146.
415. Baldwin SA. *Psychological Statistics and Psychometrics Using Stata*. Stata Press; 2019.
416. Tavakol M, Dennick R. Making sense of Cronbach's alpha. *International Journal of Medical Education*. 2011;2:53-55.
417. Taber KS. The Use of Cronbach's Alpha When Developing and Reporting Research Instruments in Science Education. *Research in Science Education*. 2018;48(6):1273-1296.
418. Matsunaga M. How to Factor-Analyze Your Data Right: Do's, Don'ts, and How-To's. *International Journal of Psychological Research*. 2010;3(1):97-110.
419. Polit DF. Getting serious about test–retest reliability: a critique of retest research and some recommendations. *Quality of Life Research*. 2014;23(6):1713-1720.
420. Cook DA, Beckman TJ. Current Concepts in Validity and Reliability for Psychometric Instruments: Theory and Application. *The American Journal of Medicine*. 2006;119(2):166.e7-166.e16.
421. Frost MH, Reeve BB, Liepa AM, Stauffer JW, Hays RD. What Is Sufficient Evidence for the Reliability and Validity of Patient-Reported Outcome Measures? *Value in Health*. 2007;10:S94-S105.
422. Landis JR, Koch GG. The Measurement of Observer Agreement for Categorical Data. *Biometrics*. 1977;33(1):159-174.
423. Taherdoost H, Sahibuddin S, Jalaliyoon N. Exploratory factor analysis; concepts and theory. In: Balicki J, ed. *Advances in Applied Pure Mathematics*. Poland; 2014:375-382.
424. Kim H, Ku B, Kim JY, Park Y-J, Park Y-B. Confirmatory and exploratory factor analysis for validating the Phlegm Pattern Questionnaire for healthy subjects. *Evidence-Based Complementary Alternative Medicine*. 2016;2016
425. Ximénez C. Recovery of weak factor loadings in confirmatory factor analysis under conditions of model misspecification. *Behavior Research Methods*. 2009;41(4):1038-1052.
426. Sim J, Wright CC. The Kappa Statistic in Reliability Studies: Use, Interpretation, and Sample Size Requirements. *Physical Therapy*. 2005;85(3):257-268.
427. Kost RG, de Rosa JC. Impact of survey length and compensation on validity, reliability, and sample characteristics for Ultrashort-, Short-, and Long-Research Participant Perception Surveys. *J Clin Transl Sci*. 2018;2(1):31-37.
428. Montenegro M. Subverting the universality of metadata standards: The TK labels as a tool to promote Indigenous data sovereignty. *Journal of Documentation*. 2019;75(4):731-749.
429. World Health Organisation. International classification of health interventions (ICHI). World Health Organisation. Updated 8 April 2020. https://www.who.int/classifications/ichi/en/
430. Kite E, Davy, C., Gibson, O., McBride, K. Brown, A., . Aboriginal and Torres Strait Islander peoples' perceptions of quality of life and wellbeing and how they are measured: a systematic review protocol. *JBI Database of Systematic Reviews and Implementation Reports,*. 2014;12(7):138-147.
431. Curtis E, Jones R, Tipene-Leach D, et al. Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. *International Journal for Equity in Health*. 2019;18(1):174.
432. Coombes J, Hunter K, Mackean T, Ivers R. The Journey of Aftercare for Australia's First Nations Families Whose Child Had Sustained a Burn Injury: A qualitative study. *BMC Health Service Research*. 2020;(Accepted for Publication)

433. Williams HM, Hunter K, Clapham K, Ryder C, Kimble R, Griffin B. Efficacy and cultural appropriateness of psychosocial interventions for paediatric burn patients and caregivers: a systematic review. *BMC Public Health*. 2020;20(1):284.
434. Shepherd CCJ, Li J, Cooper MN, Hopkins KD, Farrant BM. The impact of racial discrimination on the health of Australian Indigenous children aged 5–10 years: analysis of national longitudinal data. *International Journal for Equity in Health*. 2017;16(1):116.
435. Reid P, Robson B. Understanding health inequities. In: Mulholland M, ed. *Hauora: Māori Standards of Health IV: A study of the years 2000-2005*. Reed; 2006:3-10.
436. Senese LC, Wilson K. Aboriginal urbanization and rights in Canada: Examining implications for health. *Social Science & Medicine*. 2013;91:219-228.
437. Hansen KL. Ethnic discrimination and health: the relationship between experienced ethnic discrimination and multiple health domains in Norway's rural Sami population. *International Journal of Circumpolar Health*. 2015;74(1):25125.
438. Katz A, Brownell M. Ensuring Indigenous participation in research on the health and well-being of Indigenous Peoples. *Canadian Medical Association Journal*. 2019;191(25)
439. Moreton-Robinson A. Chapter 9: Toward a New Research Adenga Foucault, Whiteness, and Sovereignty. In: Moreton-Robinson A, ed. *The White Possessive: Property, Power and Indigenous Sovereignty*. University of Minnesota Press; 2015:125-135.
440. Harris P, Baum F, Friel S, Mackean T, Schram A, Townsend B. A glossary of theories for understanding power and policy for health equity. *Journal of Epidemiology and Community Health*. 2020;74(6):548-552.
441. Moreton-Robinson A. Chapter 2: The House That Jack Built: Britishness and White Possession. In: Moreton-Robinson A, ed. *The White Possessive: Property, Power and Indigenous Sovereignty*. University of Minnesota Press; 2015:19-31.
442. Moreton-Robinson A. Towards a new research agenda? Foucault, whiteness and indigenous sovereignty. *Journal of Sociology*. 2006;42(4):383-395.
443. Rea S, Wood F. Minor burn injuries in adults presenting to the regional burns unit in Western Australia: A prospective descriptive study. *Burns*. 2005;31(8):1035-1040.
444. The Project - 02 Jun 2020. *The Project*. Campbell C.
445. Eades A-M, Hackett M, Raven M, Liu H, Cass A. The impact of vicarious trauma on Aboriginal and/or Torres Strait Islander health researchers. *Public Health Research and Practice*.
446. Australian Bureau of Statistics. *Socio-Economic Indexes for Areas (SEIFA)*. 2011.
447. G Shakespeare P. *Standards and quality in burn treatment*. vol 27. 2002:791-2.

Appendices

Appendix A: Patient inclusion process for BRANZ data (Chapter 4 and 5).

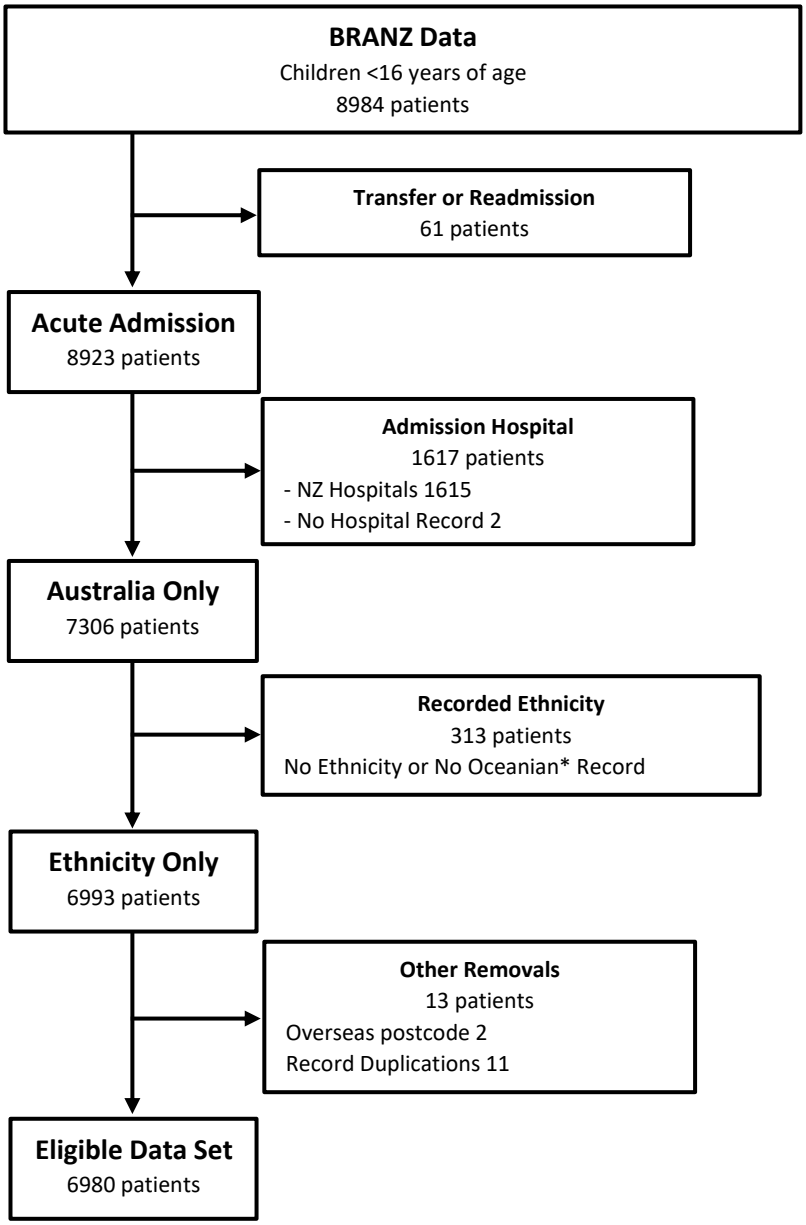


Figure B.1: Patient inclusion process for BRANZ data.

*Oceanian variable in BRANZ is a patient's cultural affiliation, defined as where a patient feels that they belong (19).

Appendix B: Variables extracted and created from BRANZ data (Chapter 4 and 5).

Variable		Source	Definition
	Items (ICD-10-AM or Items)		
PROGRESS-Plus			
	Place of Residence, Race/ethnicity, Gender, Socio-economic status, All Socio-economic position, Age.	BRANZ	Equity framework, which provides factors which contribute to unequal health status [103, 179]. Note - PROGRESS-Plus was used for variables of: Gender, Age Range, ARIA, SES.
Gender			
	Male, Female, Intersex/indeterminate	BRANZ	Socio-cultural identity as reported in the BRANZ [184]
Age			
	Presented as a range	BRANZ	Age range, which the child falls into, as reported in the BRANZ.
Accessibility/Remoteness Index of Australia (ARIA)			
	RA1 Metropolitan, RA2 Inner Regional, RA3 Outer Regional, RA4 Remote, RA5 Very Remote.	BRANZ ABS	Accessibility/Remoteness Index of Australia. A geographical classification, based on the population size of a postcode to major centres [333, 334].
Socio-economic Status, Socio-Economic Indexes for Area (SES)			
	1-2 Very Low SES, 3-4 Low SES, 5-6 Medium SES, 7-8 High SES, 9-10 Very High SES	BRANZ ABS	Australian Bureau of Statistics measures, which positions postcodes on socio-economic advantage and disadvantage over a 10-point scale [334, 446].
Length of Stay (LOS) in Hospital			
	Continuous variable	BRANZ	Day of admission to day of discharge.
Injury Cause			
	*Scald, Contact, Flame, Friction, Other (*electrical, chemical, no cause of other)	BRANZ	Cause of the burns injury as reported in the BRANZ.
Percentage Total Body Surface Area (%TBSA) [383]			
	T31.00	BRANZ ICD-10-AM	Burn < 10 %TBSA
	T31.10, T31.11		Burn 10 - 19 %TBSA
	T31.20-T31.99		Burn > 19 %TBSA
Burn Depth [383, 447]			
	T20.1, T21.10-.19, T22.10-.12, T23.1, T24.1, T25.1, T26.1, T27.1, T28.1, T29.1, T30.1	BRANZ ICD-10-AM	Superficial Thickness
	T20.2, T21.20-.29, T22.20-.22, T23.2, T24.2, T25.2, T26.2, T27.2. T28.2, T29.2, T30.2		Partial Thickness
	T20.3, T21.30-.39, T22.30-.32, T23.3, T24.3, T25.3, T26.3, T27.3, T28.3, T29.3, T30.3		Full Thickness
Bacterial Infection [383]			
	B95.0-B95.5, B95.41, B95.42, B95.48	BRANZ ICD-10-AM	Streptococcus Infection [383]
	B95.6-95.8		Staphylococcus Infection
Burn Dressing [383]			
	30010-00	BRANZ ICD-10-AM	< 10 % Body Surface Area
	30014-00		≥ 10% Body Surface Area
Burn Debridement [383]			
	90686-00	BRANZ ICD-10-AM	Nonexcisional
	30017-01, 30020-00		Excisional
Split Skin Graft [383]			
	45406-00	BRANZ ICD-10-AM	> 3 % Body Surface Area
	45409-00, 45412-00, 45415-00, 45418-00, 45460-00, 45464-00, 45468-00, 45471-00, 45474-00, 45477-00, 45480-00, 45483-00		≤ 3 % Body Surface Area (grafting as ≤ 3% includes 3-6, 6-9, 9-12, 12-15, 15-20, 20-30… > 80%)
Allied Health Intervention [383]			
	95550-02, -03	BRANZ ICD-10-AM	Occupational Therapy or Physiotherapy
	95550-01, -10		Social Worker or Psychology

	95550-00, -05, -06, -08, -09		Dietetics, Speech Pathology, Audiology, Prosthetics and Orthotics, or Pharmacy

Table D.1 – Variables extracted and created from data source with their definitions.

Appendix C – OOPHE Study Participant Information (Chapter 6)

C.1 Participant information Sheet

The George Institute for Global Health Australia

UNSW SYDNEY

PARTICIPANT INFORMATION SHEET
> Out-of-Pocket Healthcare Expenditure

Invitation
You are part of the Coolamon study, which is looking at burns outcomes in Aboriginal and Torres Strait Islander children. In this study, we (research team) want to know how much your child's burns care is costing you, out of your own pocket. To do this we want to create a survey tool that records this information. We want to make this tool especially for Aboriginal and Torres Strait Islander families, because the survey tools out there that currently do this haven't been made in a way to suit Aboriginal and Torres Strait Islander people. We would like to know if you would like to participate in this part of the study

This study is being run by:
- Rebecca Ivers, Professor, The George Institute for Global Health
- Andrew Holland, Professor, Westmead Hospital
- Tamara Mackean, Doctor, The George Institute for Global Health
- Kate Hunter, Doctor, The George Institute for Global Health
- Courtney Ryder, PhD Student, The George Institute for Global Health

Before you decide if you want to join this small study, take some time to read over the information in this sheet. Also discuss it with any family members or researchers before you decide.

1. What is the purpose of this study?
We want to make a survey tool that records all the costs you have had to pay out of your own pocket for your child's burns care and how this has impacted you and your family.

2. Why have I been invited to participate?
You are part of the Coolamon study and are at your 12 month follow up interview.

3. What if I don't want to participate? Or want to redraw later on?
If you don't want to participate you don't have to. If you do participate and decide later you don't want to you can stop too. Whatever you decide, it will not affect your relationship with the staff caring for your child or being in the Coolamon study.

4. What is involved?
If you decide yes, we will ask you to sign a Participant Consent form for this small study. This form says you are happy to participate in two surveys which record information on the amount of money you have had to pay out of your own pocket for your child's burns care.

The Coolamon site researcher will then go through a survey with you, recording your answers to questions. This should only take 10 minutes. The researcher will then arrange another time and date to do the survey again about two weeks after the first one.

5. How is the study being paid for?
The Coolamon study is paid for by a National Health and Medical Research Grant.

6. Are there any risks involved if I participate?
There are no risks to participating in this small study. All the information you provide is de-identified, a process where we remove any information that can identify you.

7. What will I benefit from by participating in the study?
We hope the information you provide can build a great survey tool, which can be used by Aboriginal research organisations in the future and help inform policy and decrease the amount of money you have to pay out of your own pocket for healthcare.

.

8. Are there any costs associated with participating in the study?
No.

9. Will the results be confidential? How am I protected?
All information is de-identified. Only the main researcher Courtney Ryder, and the Coolamon site research assistant will need to know if you participate or not.

10. What will occur with the results of this sub-study?
The information you provide will make a survey tool to record the costs you have to pay out of your own pocket for your child's healthcare. We will also be looking to publish a research journal article and present this information at a conference. If you would like to know about the results of this small study, let us know so we can tell you.

11. What should I do if I would like to discuss the study further before I decide?
If you read this information sheet or anyone in your family had read it and you have questions, the Coolamon Research Assistant will discuss these questions with you. Courtney can also answer any extra questions you may have at your interview if you decide to participate.

12. Who should I contact if I have concerns about the conduct of the study?
Research which involves people in Australia is looked at by a group of people called a Human Research Ethics Committee (HREC). Research which involves Aboriginal and Torres Strait Islander communities, is also looked at be Aboriginal Health Research and Medical Councils. The study has had its ethical aspects approved by the HREC of:

1. [Insert hospital/university ethics]
2. [Insert Aboriginal Health Research and Medical Council]

As part of this process, we have agreed to carry out the study according to the National Statement on Ethical Conduct in Human Research along with meeting specific national guidelines around conducting research with Aboriginal and Torres Strait Islander communities.

If you have bad problems with the way this study is being done or you wish to complain to someone not in the Coolamon study, please contact either of the organisations below. You will need to tell them the study name and number (OOPHE Study, *Insert HREC number*).

Insert HREC Contact Name
Insert HREC Contact Details
Telephone: insert
Email: insert
Fax: insert

Thank you for taking the time to consider this small study.
If you wish to take part in it, please sign the consent form.
This information sheet is for you to keep.

C.2 Participant Consent Form

The George Institute
for Global Health Australia

The George Institute for Global Health
ABN 90 085 953 331

Level 5, 1 King Street
Newtown NSW 2042
AUSTRALIA

PO Box M201
Missenden Road
NSW 2050 AUSTRALIA

T: +61 2 8052 4300
F: +61 2 8052 4301

info@georgeinstitute.org.au
www.georgeinstitute.org

PARTICIPANT CONSENT FORM
Coolamon Study > Out-of-Pocket Healthcare Expenditure
(HREC NUMBER)
Coordinating Researcher: Prof Rebecca Ivers, Researcher: Courtney Ryder

I agree to take part in this sub-study to the Coolamon study. In giving my consent, I state that:

- I understand the purpose of the study along with any risks or benefits involved.
- I have read the participant information sheet and have been able to discuss my involvement in the study with the researchers if I wished to do so. The researchers have answered any questions that I have about the study and I am happy with these answers.
- I understand that being in this sub-study is completely voluntary and I do not have to take part.
- I understand I can withdraw from this sub-study as any time.
- I understand the information that is collected about me and my family during this sub-study will be stored securely and will on be used for the purposes that have been agreed to. I understand that information about me will only be told to others with my permission, except as required by law.
- I understand that the results of this study maybe published and that publications will not contain my name and I will not be able to be identified.

☐ I agree to the Terms and Conditions for the use of the sub-study application

☐ I understand all of the above and agree to take part in the study

☐ I wish to receive a copy of the results (if box is not checked then results will not be sent to you)
Contact me by email:
Send me a hard copy:

Participant Signature	Researchers Signature
Participant Name:	Researchers Name:
Date	Date:

C.3 Yarning Script

Hi, I'm Courtney and am a PhD student from The George Institute for Global Health working on the Coolamon study. Thank you so much for wanting to be part of my small study, looking at costs in burns care. The Coolamon Research Assistant (insert name) would have given you a Participant Information sheet to have a look through and discuss with your family. Just to go over this information a little, I am hoping what I get from this interview, will help the research team learn more about how much burns treatment for your child is costing you, out of your own pocket. This information is going to develop a survey tool to record this information, only for Aboriginal and Torres Strait Islander families. At the moment in Australia there is no survey tool that does this for our mob. By learning more about the costs and how it affects your family, hopefully we can create change in the future so healthcare won't cost as much.

A little bit of time has passed since you spoke to (RA name) and signed the consent form. Do you have any questions or concerns about participating in this small study?

We are going to start the study in a minute, but I want you to know that you can stop this interview at any time, just let me know. If you feel uncomfortable or are not happy with any of the questions, please let me know as well. Because at the end of the day we want to have a survey tool that families feel comfortable filling out.

The interview will could take up to an hour of your time and hopefully we will just be having a bit of a yarn around all of this stuff. So I can look at all the information later I need to record this study and am going to start recording now.

1. In our families, we have various roles and responsibilities. What are some things that you are or you feel responsible for in your life?
   Rephrased version: Family life is busy, especially when you have little ones or you're caring for older family. What are some of the things that your family relies on you for or things they expect you to do?

2. Even with Medicare, private health insurance, close the gap, healthcare is still expensive in Australia. How easy or difficult has it been for your family to access appropriate and affordable healthcare (services, allied health, medication)?
   a. Follow up - what are some of the barriers or difficulties you and your family have faced in accessing treatment?

   Rephrased version: Not all of our healthcare is covered by the government and sometimes we have to pay money for healthcare or healthcare items such as medicine out of our own pocket. Thinking about this and some of the costs you have had to pay, how easy or hard has it been for you or your family to get all of the healthcare you need, such as medicine, following up at the doctors or specialist appointments?

3. How have extra healthcare costs, such as medications or bandages from the pharmacy, or transport to and from hospital, impacted on you and your family with your child's burn care?

Rephrased question: Thinking about your little one's burn now and all of the treatment they have had to have, what type of things have you had to purchase out of your own pocket for them? Has this meant that you haven't been able to get other things you or other family members might need?

4. Sometimes money can get very stretched for families, especially when bills come in, doing grocery shopping because you have a full house, for birthdays, or even funerals. In times like this what are some of the things you and your family do to get through these times? *Rephrased question: Food, bills, helping family out means money can go quickly and it can seem like sometime between pay days. What are some of the things you and your family do to get by when you're stuck waiting for pay day? Have you had to do this for your little one's burns care?*

5. I am going to provide you with a survey which was created in Australia to record some of the things we have been talking about today. What I would like to do now is go through each of the questions in Section D, Section E, and Section F (Attachment 10 – Essue Survey).
    a. What do you think about this question? Is it comfortable or uncomfortable?
    b. What don't/do you like about this questions?
        i. How would you change it to make it better?

Rephrased question: So in your participant sheet and I mentioned before there is a survey tool in Australia that has been made to record some of these questions around healthcare costs. You would have been given a copy of this when you signed the consent. I want to talk about the questions in this survey question now.

A. What do you think about this question, do you like it or not?
B. What do you like/not like about this question?
C. What do you think could make it better?

This brings us to the end of our interview. Is there anything else you would like to say about OOPHE that we haven't talked about today?

I would really like to thank you for giving me your thoughts today on this really important matter. I wish you and your family all the best with the on going burns care for your child.

Appendix D – OOPHE Survey & Expert Panel Documents (Chapter 7)

D.1 Expert Panel Invitation

The George Institute for Global Health Australia

The George Institute for Global Health
ABN 90 085 983 331

Level 5, 1 King Street
Newtown NSW 2042
AUSTRALIA

PO Box M201
Missenden Road
NSW 2050 AUSTRALIA

T: +61 2 8052 4300
F: +61 2 8052 4301

ryder@georgeinstitute.org.au
www.georgeinstitute.org

DATE

Title Name
Position
Address
Address
Town State Etc

Dear Title Name

Understanding Out of Pocket Healthcare Expenditure (OOPHE) for Burns Treatment in Aboriginal and Torres Strait Islander Families

The OOPHE study is part of Courtney Ryder's doctoral studies. It is a unique project, in that it is the first study seeking to understand the impact of OOPHE on Aboriginal and Torres Strait Islander families, whose child has sustained a burns injury. Given this significance, the research team is mindful of ensuring that an OOPHE tool is created, which is appropriate for use with Aboriginal and Torres Strait Islander families.

Psychometric assessment is the process used to design and assess patient recorded outcome measures. For this study, Ryder is using a 'gold standard' process, in which 'end users' and 'content experts' are consulted for the overall design and development of the OOPHE. Already yarning sessions with Aboriginal families, impacted by burn injuries have occurred, the main themes from these sessions have informed the design of the current OOPHE tool. Psychometric assessment also requires judgement quantification from experts related to this tool. Courtney is contacting you as she is hoping that you may have availability to be a content expert for assessing the OOPHE tool. Your name was suggested, as being an expert in Aboriginal and Torres Strait Islander research/Injury research/health economics, from a member of Ryder's supervision team.

Participation as a content expert in this study would roughly take about 60 minutes. It requires you assessing each question on a 4-point Likert scale with consideration of the main themes. Responses from you and other the content experts will be collated, reviewed and used to modify the OOPHE tool. Ryder will also calculate the item-level content validity index, for each item and the inter-rater reliability between content experts. This process will allow the first reiteration of a measure for OOPHE specific to Aboriginal and Torres Strait Islander communities, to be developed and further assessed. Ryder will also acknowledge your participation in any publications associated with the psychometric assessment of the OOPHE tool.

Kind Regards
Courtney Ryder
PhD Student, Injury Division
The George Institute for Global Health

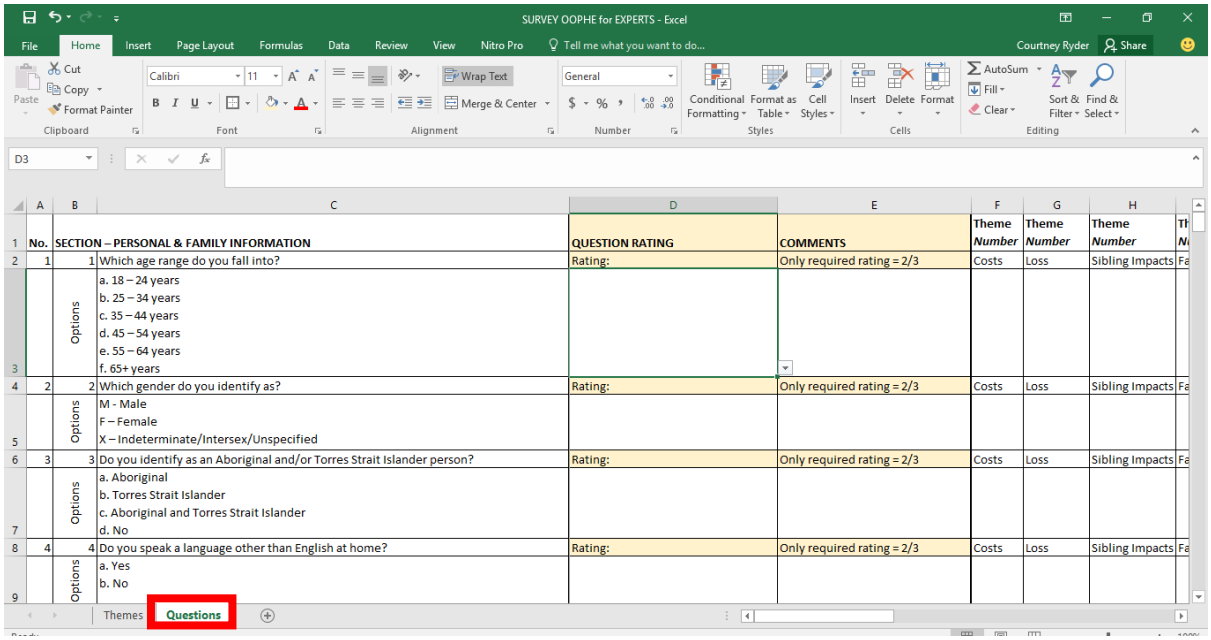
Affiliated with

UNSW SYDNEY

D.2 Expert Panel Instructions

Survey Instructions for Content Experts

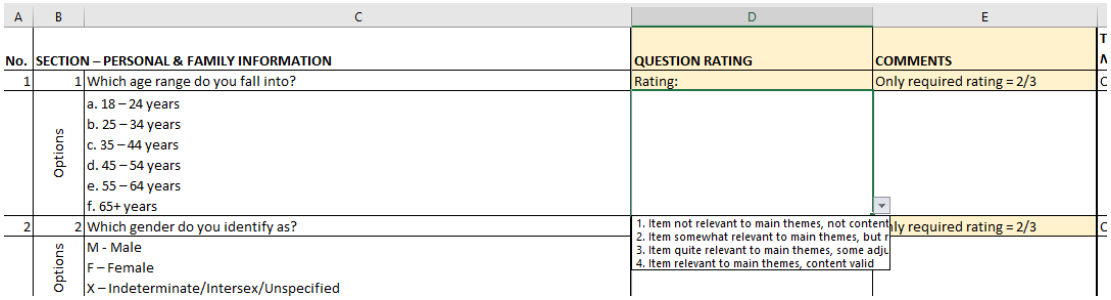
Please save a copy of this excel spreadsheet which you can email back to me with your results.



No.		SECTION – PERSONAL & FAMILY INFORMATION	QUESTION RATING	COMMENTS	Theme Number	Theme Number	Theme Number
1	1	Which age range do you fall into?	Rating:	Only required rating = 2/3	Costs	Loss	Sibling Impacts
	Options	a. 18 – 24 years b. 25 – 34 years c. 35 – 44 years d. 45 – 54 years e. 55 – 64 years f. 65+ years					
2	2	Which gender do you identify as?	Rating:	Only required rating = 2/3	Costs	Loss	Sibling Impacts
	Options	M - Male F – Female X – Indeterminate/Intersex/Unspecified					
3	3	Do you identify as an Aboriginal and/or Torres Strait Islander person?	Rating:	Only required rating = 2/3	Costs	Loss	Sibling Impacts
	Options	a. Aboriginal b. Torres Strait Islander c. Aboriginal and Torres Strait Islander d. No					
4	4	Do you speak a language other than English at home?	Rating:	Only required rating = 2/3	Costs	Loss	Sibling Impacts
	Options	a. Yes b. No					

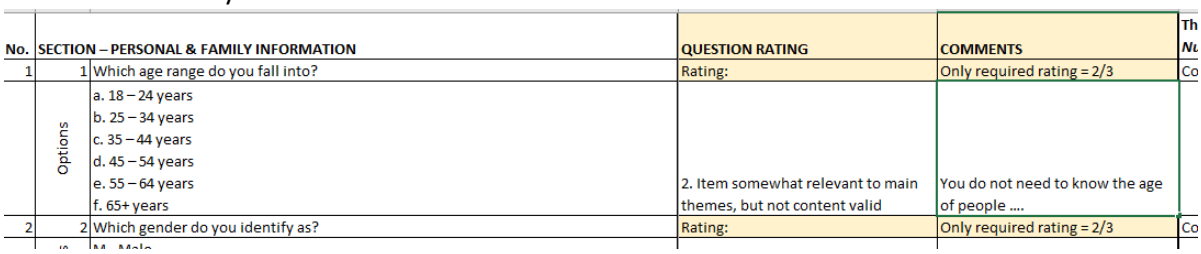
The survey is located on the Questions tab in the excel names SURVEY OOPHE for Experts

You can rate each of the questions, by selecting an option from the drop down menu



No.		SECTION – PERSONAL & FAMILY INFORMATION	QUESTION RATING	COMMENTS
1	1	Which age range do you fall into?	Rating:	Only required rating = 2/3
	Options	a. 18 – 24 years b. 25 – 34 years c. 35 – 44 years d. 45 – 54 years e. 55 – 64 years f. 65+ years		
2	2	Which gender do you identify as?	1. Item not relevant to main themes, not content 2. Item somewhat relevant to main themes, but r 3. Item quite relevant to main themes, some adju 4. Item relevant to main themes, content valid	ly required rating = 2/3
	Options	M - Male F – Female X – Indeterminate/Intersex/Unspecified		

If you select option 2 or 3, there is a section for you to comment on how this question should be modified or why it is not suitable.

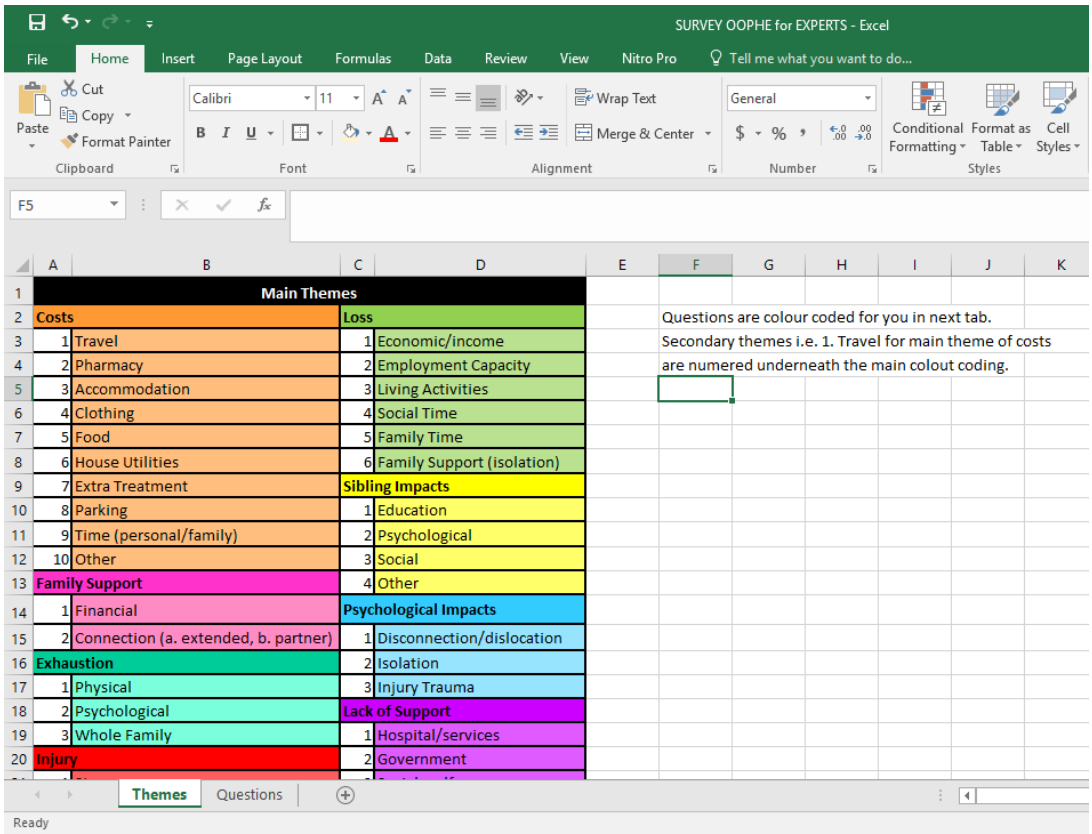


No.		SECTION – PERSONAL & FAMILY INFORMATION	QUESTION RATING	COMMENTS
1	1	Which age range do you fall into?	Rating:	Only required rating = 2/3
	Options	a. 18 – 24 years b. 25 – 34 years c. 35 – 44 years d. 45 – 54 years e. 55 – 64 years f. 65+ years	2. Item somewhat relevant to main themes, but not content valid	You do not need to know the age of people ....
2	2	Which gender do you identify as?	Rating:	Only required rating = 2/3

If you forget which theme the question relates to you can move right with the cursor to check

A	B	C	J	K	L	M	N	O
No.		SECTION – PERSONAL & FAMILY INFORMATION	Theme *Number*	Theme *Number*	Theme *Number*	Theme *Number*	Theme	Theme
1	1	Which age range do you fall into?	Psychological Impacts	Exhaustion	Lack of Support	Injury	Finanical Stress	Progress-PLUS
	Options	a. 18 – 24 years b. 25 – 34 years c. 35 – 44 years d. 45 – 54 years e. 55 – 64 years f. 65+ years						
2	2	Which gender do you identify as?	Psychological Impacts	Exhaustion	Lack of Support	Injury	Finanical Stress	Progress-PLUS
	ions	M - Male F – Female						

All of the themes which were drawn from the yarning session can be found on the 'Themes' tab



	Main Themes		
Costs		Loss	
1	Travel	1	Economic/income
2	Pharmacy	2	Employment Capacity
3	Accommodation	3	Living Activities
4	Clothing	4	Social Time
5	Food	5	Family Time
6	House Utilities	6	Family Support (isolation)
7	Extra Treatment	Sibling Impacts	
8	Parking	1	Education
9	Time (personal/family)	2	Psychological
10	Other	3	Social
Family Support		4	Other
1	Financial	Psychological Impacts	
2	Connection (a. extended, b. partner)	1	Disconnection/dislocation
Exhaustion		2	Isolation
1	Physical	3	Injury Trauma
2	Psychological	Lack of Support	
3	Whole Family	1	Hospital/services
Injury		2	Government

A larger description of these themes can be found under the 'OOPHE Study Phase 2' document.

If you have any questions, concerns or problems with the excel sheet, please contact me at your earliest convenience.

D.3 OOPHE Survey

Oophe Phase 2 Survey - Survey 1

Welcome to the Out-of-Pocket Healthcare Expenditure Survey for Aboriginal and Torres Strait Isalnder families.

In this survey we will ask you a range of questions related to healthcare, money and family. It really is about how much you have had to pay out of your own pocket for healthcare. The questions and wording in the survey were made to get information about hospitalisation from an injury a child may have had. So this will seem a little strange, because you may never have been to hospital for your child before. Do not worry about this! We are just testing the survey and questions generally with Aboriginal and/or Torres Strait Islander families. So what we would like you to do, is try to answer all of the questions to the best of your ability. It may help to remember a past time you have had to be in hospital with your child, or a young family member. We will ask you these questions again in 2 weeks' time. For this we would like you to recall the same example you used in this survey.

Thank you for wanting to participate!

WELCOME

to the 'Understanding Out of Pocket Healthcare Expenditure in Aboriginal and Torres Strait Islander Families' survey

NOTE
We use your first name, mobile and email address to remind you in 2 weeks to do the survey again. We also use this information to match your 1st survey to your 2nd survey for our data analysis. Please rest assured, before data analysis starts this information is removed and your surveys are deidentified. We also do not hand this information over to other people or organisations.

What is your first name? Or what do you prefer to be called? _____

Please enter the best mobile number to contact you on currently. In two weeks time we will send you a text to remind you to complete the survey again with the survey link. This number will only be used to contact you in two weeks time, it will not be shared with anyone else.

Mobile Number _____

Please enter the best email address to contact you on. We will send you an email reminder in two weeks to participate in the survey again with the survey link. This email will only be used to contact you in two weeks time, it will not be shared with anyone else.

Email _____

Please enter your Email again _____

IMPORTANT
The questions of this survey relate to you ([first_name]), your family and money you have needed to pay for healthcare treatment. The questions are worded to understand how much money an Aboriginal and/or Torres Strait Islander family has had to pay out of their own pocket for healthcare, along with other family impacts. This may seem strange, as your child may have never been to hospital. Do not worry about this. We are testing the survey generally with Aboriginal and/or Torres Strait Islander families. So what we would like you to do [first_name], is answer the questions as well as you can. It may help to imagine a past situation where you have had to be in hospital for your child, or perhaps another young family member. We will ask all of the same questions in two weeks' time. It is important that you answer every question.

LASTLY, once you start the survey there is no save option to come back. The first time it may take you 30-50 minutes to complete. Second time round will be much quicker. So if now is a bad time, just keep the link and start it when it is a better time :)

[first_name], have any of your children had to stay overnight in hospital?	◯ Yes ◯ No
[first_name], have any of your children had an injury which has required hospitalisation?	◯ Yes ◯ No

Personal & Family Information	
[first_name] do you feel that the treatment and care that your child has needed for their injury, has impacted your family financially?	◯ Definitely impacted ◯ It has been impacted ◯ Somewhat impacted ◯ Not really impacted ◯ Not impacted at all
Which age range do you fall into [first_name]?	◯ 18 - 24 years ◯ 25 - 34 years ◯ 35 - 44 years ◯ 45 - 54 years ◯ 55 - 64 years ◯ 65+ years
Which gender do you identify as?	◯ M - Male ◯ F - Female ◯ X - Indeterminate/Intersex/Unspecified
[first_name], do you identify as an Aboriginal and/or Torres Strait Islander person?	◯ Aboriginal ◯ Torres Strait Islander ◯ Aboriginal and Torres Strait Islander ◯ No
What best describes your relationship status [first_name]?	◯ Single ◯ Married ◯ De Facto ◯ Separated ◯ Widowed ◯ Rather not say
Do you speak a language other than English at home?	◯ Yes ◯ No
What langauge is this?	_____
[first_name], how many children under the age of 16 years are normally in your care at your house?	◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5+
Do any of these children identify as an Aboriginal and/or Torres Strait Islander person?	◯ Yes - All of the children ◯ Yes - Some of the children ◯ No - None of the children
[first_name], how many adults and people over 16 years, including you, currently live in your house?	◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5+

[first_name], where you live, your accommodation is it?	◯ Rented (private) ◯ Rented (social housing) ◯ Own Home (with mortgage) ◯ Own Home (no mortgage) ◯ I would rather not say ◯ Other
If other what is it?	_____
What is the postcode where you live [first_name]?	_____

Education & Employment	
What is the highest education level you have been able to complete [first_name]?	◯ Primary School ◯ Secondary School ◯ TAFE Diploma or Certificate ◯ University Undergraduate ◯ University Postgraduate ◯ I was not able to attend school
[first_name] are you currently working?	◯ Yes - employed ◯ Not employed ◯ Not employed - I'm studying ◯ Not employed - due to medical/caring responsibilities ◯ Not employed - I am retired ◯ Not employed - I retired early due to medical/caring responsibilities ◯ Not employed - other
If other what is it?	_____
If you do work or study, what best describes your week [first_name]?	◯ I am employed full time (more than 20 hrs a week) ◯ I am employed part time (less than 20 hrs a week) ◯ I am employed but on sick/carers leave ◯ I am a full time student ◯ I am a part time student ◯ I am looking for work or to study ◯ Other
If other what is it?	_____
[first_name], if you have worked what has been your main job or occupation?	_____

Injury Impact & Treatment	
[first_name], did your child have to go to the hospital for their injury?	◯ Yes ◯ No
[first_name], did you or a family member stay in hospital with your child after your child's injury?	◯ Yes ◯ No
How many nights did you have to stay [first_name]?	_____
Which family member stayed with your child in hospital? (more than 1 options can be selected)	☐ Mum ☐ Dad ☐ Grandparent ☐ Auntie ☐ Uncle ☐ Family rotated around ☐ Other
If Family rotated around, or Other was selected, could you tell us a little about this?	_____
When your child was in hospital for their injury, was it easy for the family member who stayed in hospital to get reasonable meals and snacks?	◯ Yes, the hospital provided this ◯ Yes, there were local shops close by ◯ Yes, from the hospital café/cafeteria ◯ Yes, other ◯ No, why not (expensive, availability)
If Other was selected what was it?	_____
When your child was first injured and in hospital, did the family member who stayed in hospital, have to spend money out of their own pocket for things while there (food, transport, accommodation, toiletries)?	◯ Yes ◯ No
If yes how much in total did they roughly spend for FOOD	◯ $0 ◯ $1-$20 ◯ $21-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$400 ◯ $401+
If yes how much in total did they roughly spend for ACCOMMODATION	◯ $0 ◯ $1-$20 ◯ $21-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$400 ◯ $401+

If yes how much in total did they roughly spend for TRANSPORT/PARKING	◯ $0 ◯ $1-$20 ◯ $21-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$400 ◯ $401+
If yes how much in total did they roughly spend on TOILETRIES?	◯ $0 ◯ $1-$20 ◯ $21-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$400 ◯ $401+
If yes how much in total did they roughly spend for ENTERTAINMENT?	◯ $0 ◯ $1-$20 ◯ $21-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$400 ◯ $401+
If yes how much in total did they roughly spend on CLOTHING?	◯ $0 ◯ $1-$20 ◯ $21-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$400 ◯ $401+
If yes how much in total did they roughly spend for OTHER expenses related to the injury and hospital stay?	◯ $0 ◯ $1-$20 ◯ $21-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$400 ◯ $401+
If over $400+, how much did you spend? What was it for?	_____
Were you or any family members given vouchers from the hospital to help pay for things while you were there?	◯ Yes ◯ No
If YES - what was the total amount for HOSPITAL CAFE or CAFETERIA vouchers?	◯ No voucher provided for this ◯ $1-$20 ◯ $21-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201+

If YES - what was the total amount for HOSPITAL PARKING vouchers?	◯ No voucher provided for this ◯ $1-$20 ◯ $21-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201+
If YES - what was the total amount for ENTERTAINMENT vouchers?	◯ No voucher provided for this ◯ $1-$20 ◯ $21-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201+
If yes, but it was something different, what was this and how much for?	_____
[first_name], when your child was discharged, you may have needed things such as medication, bandages or equipment to treat your child's injury at home. [first_name] did the hospital give you this, or did you have to pay for it out of your own pocket?	◯ Yes - they provided everything (such as medication, bandages, and equipment) ◯ Yes - they provided most things (such as medication) but we still had to buy things ◯ No - we had to buy out of our own pocket everything to treat our child's injury at home ◯ No - my child did not need any extra treatment at home after leaving hospital

Care Responsabilities	
[first_name] does your child require extra support for everyday activities because of their injury?	◯ No ◯ Yes, but because they are young not because of the injury ◯ Yes, this support is provided by their parents ◯ Yes, this support is provided by another family member ◯ Yes, care provided by other, such as support service
If YES, could you briefly tell us in what way they need extra support?	_____
[first_name], do you feel that your child's injury influences or impacts on their day-to-day activities?	◯ Yes ◯ No
How long do you feel your child's injuries will affect them?	◯ It doesn't ◯ A few months ◯ A year or so ◯ Around 5 years ◯ Around 10 years ◯ For the rest of their life
How does your child's injury impact on them emotionally?	◯ Nothing at all ◯ A little ◯ Sometimes ◯ A fair amount ◯ All the time ◯ Don't know
In general today [first_name], how would you rate the health of your child?	◯ Excellent ◯ Very good ◯ Good ◯ Fair ◯ Poor ◯ Don't know
[first_name], have you found that you have been impacted emotionally, by your child's injury?	◯ Nothing at all ◯ A little ◯ Sometimes ◯ A fair amount ◯ All the time

Ongoing Injury Treatment - Hospital Follow Up	
[first_name], did you have follow up treatment for your child's injury?	◯ No ◯ Yes, Outpatient Only ◯ Yes, Hospital and Outpatient ◯ Yes, Hospital Only
READMISSION TREATMENT	
How many times has your child had to be rehospitalised for follow treatment of their injury?	_____
Did these rehospitalisations occur at the same hospital where their main treatment occurred?	◯ Yes ◯ No
[first_name], using your normal mode of transport for rehospitalisation, how long does it take you to get to the hospital for this?	◯ 0-30mins ◯ 30mins-1hr ◯ 1-2hrs ◯ 2-3hrs ◯ 3hrs ++
If above 3hrs, how many hrs does it take? [first_name] feel free to briefly describe the travel process if you need.	_____
What type of transport(s) do you use to get to get to the hospital? ([first_name] more than 1 options can be selected)	☐ Flights ☐ Own car ☐ Borrowed car ☐ Hire Care ☐ Train ☐ Tram ☐ Bus ☐ Taxi/Uber ☐ Walking
[first_name], for these rehospitalisations, what is the max amount of nights you have needed to stay?	_____
What was the smallest amount of nights your child had to stay in hospital during rehospitalisation?	_____
[first_name], how many day surgery reshospitalisations has your child had? (this is where they are not required to stay overnight in hospital)	_____
During most of these rehospitalisations [first_name], which family member generally stayed with your child?	☐ Mum ☐ Dad ☐ Grandparent ☐ Auntie ☐ Uncle ☐ Family rotated around ☐ Other
If Other, or Family rotated around [first_name], could you briefly describe this?	_____

[first_name] thinking back to when your child has had to go back and be readmitted to hospital to have more treatment for their injury. How much would your family have to spend on the following things generally? ($$ value selected)	
Transport (fuel, train, bus, taxi, uber)	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
Parking	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
Food	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
Accommodation	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
Entertainment	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
Childcare, crèche, out of hours school care, paid child minding	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
Other expenses not listed.	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
If Other was selected, could you briefly tell us what these were?	_____

[first_name], was it easy for the family member who stayed in hospital to get reasonable meals and snacks while in hospital?	◯ Yes, the hospital provided this ◯ Yes, there were local shops close by ◯ Yes, from the hospital café/cafeteria ◯ Yes, other ◯ No, why not (expensive, availability)
[first_name] were you, or any family members given vouchers from the hospital to help pay for things while you were there for readmissions?	◯ Yes ◯ No
If yes, how much for the HOSPITAL CAFE or CAFETERIA?	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201+
If yes, how much for PARKING?	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201+
If yes, how much for ENTERTAINMENT?	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201+
If yes, how much for OTHER?	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201+
If yes, and OTHER what was it and for how much?	_____
[first_name] when your child was discharged from readmission, did the hospital provide you with extra medication, bandages and equipment for your child's care at home?	◯ Yes, they provided everything everytime ◯ Yes, they provided most things when we left, we had to buy a few things ◯ No, we had to purchase all medications and equipment when we left the hospital ◯ No, but because my child didn't need any

[first_name] please think about your answers for the next three questions with the face scale in the provided image.

1	2	3	4	5	Don't
Nothing At all	Slightly	Moderately	Very	Extremely	**Know?**

Hospital readmissions for your child's injury can be a challenge. For these readmissions you may have needed to organise and arrange things, such as, taking leave from work, care for your other children, accommodation, travel. Using the faces in the images above, how STRESSFUL has this been for you, [first_name], to ARRANGE?	◯ 1 - Nothing at all ◯ 2- Slightly ◯ 3 - Moderately ◯ 4 - Very ◯ 5 - Extremely ◯ Don't know
Using the faces in the images above, how DISRUPTIVE are these rehospitalisation on your family [first_name]?	◯ 1 - Nothing at all ◯ 2- Slightly ◯ 3 - Moderately ◯ 4 - Very ◯ 5 - Extremely ◯ Don't know
Using the faces in the images above, how STRESSFUL do you find these hospitalisations on your family [first_name]?	◯ 1 - Nothing at all ◯ 2- Slightly ◯ 3 - Moderately ◯ 4 - Very ◯ 5 - Extremely ◯ Don't know
OUTPATIENT TREATMENT	
How many outpatient appointments has your child attended [first_name]?	_____
How many outpatient appointments does your child have scheduled (in the future)?	_____
[first_name], is your outpatient treatment at the same hospital that your child attended for their main treatment?	◯ No ◯ Yes ◯ Some of their treatment is at the same hospital
Using the general mode of transport for follow up appointments [first_name], how long does it take you to get to the hospital for follow up treatment?	◯ 0-30mins ◯ 30mins-1hr ◯ 1-2hrs ◯ 2-3hrs ◯ 3hrs ++
If more than 3 hours, how many hours is it?	_____
What type of transport(s) do you use to get to get to the hospital? ([first_name] more than 1 options can be selected)	☐ Flights ☐ Own car ☐ Borrowed car ☐ Hire Care ☐ Train ☐ Tram ☐ Bus ☐ Taxi/Uber ☐ Walking
[first_name] do you have to stay away from home to be able to attend?	◯ No, it is generally done in a morning/afternoon ◯ No, it is generally done over a whole day ◯ Yes, we stay overnight
If yes, how many nights do you stay away?	_____

[first_name] do your other children attend these appointments?	◯ No, they stay home with a parent ◯ No, I arrange care with family/friend for them ◯ No, I arrange paid alternate care form them ◯ Yes

[first_name] when you have needed to attend a follow up appointment, roughly how much have you had to pay on that day for the following things ($$ value selected)

Transport (fuel, train, bus, taxi, uber)	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
Parking	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
Food	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
Accommodation	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
Childcare, crèche, out of hours school care or other paid care?	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
Entertainment	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+
Anything else that is not in the questions above?	◯ $0 ◯ $1-$50 ◯ $51-$100 ◯ $101-$200 ◯ $201-$300 ◯ $301+

Treatment Costs	
Sometimes [first_name], you may have had to purchase extra things for your child's injury, which you may not have considered in the past. Thinking back to your child's injury and ongoing treatment, roughly how much have you had to pay for the following out of your own money (please enter in amount without the $$ sign for each, if it is nothing just place 0).	
General Practitioner	_____
Specialists (gap payments)	_____
Medications (prescription and/non-prescription)	_____
Other Health Professional (physiotherapy/speech pathology)	_____
Medical Tests (XRay, CT, MRI, Ultrasound)	_____
Ambulance Service	_____
Medications (prescription and non prescription, such as Panadol)	_____
Medical Equipment (compression garments, bandages)	_____
Pharmacy Supplies (moisturiser, sterile water, sunscreen, special bodywash)	_____
Home modifications (ramps, plumbing)	_____
House utilities (more than normal for electricity, cooling, mobile phone)	_____
New/special clothing (sun care)	_____
New/special shoes	_____
Special foods (food intolerance, increase iron levels)	_____
Extra activities as recommended by health team (sport, kindergym)	_____
Other (such as car-shades)	_____

If you did have to purchase OTHER, what was it?	_____

[first_name], when you need to purchase supplies or attend medical appointments for your child's injury how long does it usually take you to get to the following places? (Select the usual time in duration/length [first_name])

Pharmacy/Chemist	◯ 5mins ◯ 15mins ◯ 30mins ◯ 45mins ◯ 60mins ◯ 1hr+
Large Grocery Shop (Coles, Woolworths, Aldi)	◯ 5mins ◯ 15mins ◯ 30mins ◯ 45mins ◯ 60mins ◯ 1hr+
Small Grocery Shop (IGA)	◯ 5mins ◯ 15mins ◯ 30mins ◯ 45mins ◯ 60mins ◯ 1hr+
Petrol Station	◯ 5mins ◯ 15mins ◯ 30mins ◯ 45mins ◯ 60mins ◯ 1hr+
Big Mall (with Big W, Kmart, Target)	◯ 5mins ◯ 15mins ◯ 30mins ◯ 45mins ◯ 60mins ◯ 1hr+
Smaller Mall (only one of Big W/Kmart/Target)	◯ 5mins ◯ 15mins ◯ 30mins ◯ 45mins ◯ 60mins ◯ 1hr+
Local general practitioner	◯ 5mins ◯ 15mins ◯ 30mins ◯ 45mins ◯ 60mins ◯ 1hr+

ɔcal health centre which your family attends

- ◯ 5mins
- ◯ 15mins
- ◯ 30mins
- ◯ 45mins
- ◯ 60mins
- ◯ 1hr+

Treatment Support	
[first_name] are Aboriginal and/Torres Strait family members in your house signed up for Close the Gap?	◯ Yes ◯ No ◯ Don't know what this is?
Does this include your child who has had the injury?	◯ Yes ◯ No
Since your child's injury have they accessed the NDIS (National Disability Insurance Scheme) for their injury?	◯ Yes ◯ Currently undertaking assessment ◯ No ◯ Don't know what this is?
[first_name] are you on a healthcare card?	◯ Yes ◯ No ◯ Don't know
[first_name] has your household reached the Pharmaceutical Benefits Scheme Safety net threshold?	◯ Yes ◯ No ◯ Don't know
If yes, what month did you reach it?	_____
[first_name] has your household reached the Medicare Safety net threshold?	◯ Yes ◯ No ◯ Don't know
If yes, which month was it reached?	_____
[first_name] have you tried to access extra support services for your child's injury and been ineligible for these support services?	◯ Yes ◯ No
If yes, could you tell us a little bit more about this?	_____

Household Income & Finances	
[first_name], if you or someone in your immediate family had to pay for something important, how much money could be obtained within a week?	◯ No money ◯ $0-$200 ◯ $201-$500 ◯ $501-$1000 ◯ $1001-$1500 ◯ $1501-$2000 ◯ $2001-$3000
Since your child's injury, has your immediate family needed to do any of the following things, because you needed money for living expenses [first_name]?	
Could not pay house utilities, such as gas, electricity or water on time?	◯ Yes ◯ No
Could not pay mortgage or rent on time?	◯ Yes ◯ No
Could not make minimum payment on credit card(s)?	◯ Yes ◯ No ◯ Don't have one
Could not pay car registration or insurance?	◯ Yes ◯ No ◯ Don't own a car
Could not pay transport costs? (including fuel/tyres for a car, purchasing bus/train tickets)	◯ Yes ◯ No
Could not pay mobile phone or internet on time?	◯ Yes ◯ No ◯ Don't have a mobile or internet
Cancelled extra home entertainment, such as Foxtel, Netflix, Stan, Spotify?	◯ Yes ◯ No ◯ Could not afford these in the first place
Could not pay for childcare or out of hours school care?	◯ Yes ◯ No ◯ My children do not attend childcare or out of hours care
Could not pay school or kindy fees?	◯ Yes ◯ No
Cancelled school excursions or camp, out of school sports or activities?	◯ Yes ◯ No
Could not make monthly private health insurance payment?	◯ Yes ◯ No ◯ I do not have private health
Could not pay for prescription or non-prescription medications?	◯ Yes ◯ No
Cancelled a family holiday?	◯ Yes ◯ No

Did not fill prescriptions?	◯ Yes ◯ No
Could not pay for medical appointments or tests (including GP or specialists)?	◯ Yes ◯ No
Did not attend medical appointments?	◯ Yes ◯ No
Could not pay for dental appointments?	◯ Yes ◯ No
Could not heat or cool your home?	◯ Yes ◯ No
Went without meals?	◯ Yes ◯ No

[first_name] since your child's injury, has your immediate family needed to do any of the following things because you needed money for living expenses?

Reduced home loan payments ?	◯ Yes ◯ No ◯ I do not have a home loan
Drew on savings set aside for other things (such as schooling, holiday)?	◯ Yes ◯ No ◯ I do not have savings
Moved house?	◯ Yes ◯ No
Borrowed money off of family and/or friends?	◯ Yes ◯ No
Sought assistance from welfare and/or community organisations?	◯ Yes ◯ No
Entered a loan agreement with family and/or friends?	◯ Yes ◯ No
Took out a personal loan?	◯ Yes ◯ No
Sold assets (such as household goods, toys, jewellery)?	◯ Yes ◯ No
Done something else to pay for living expenses [first_name]? Please describe:	_____

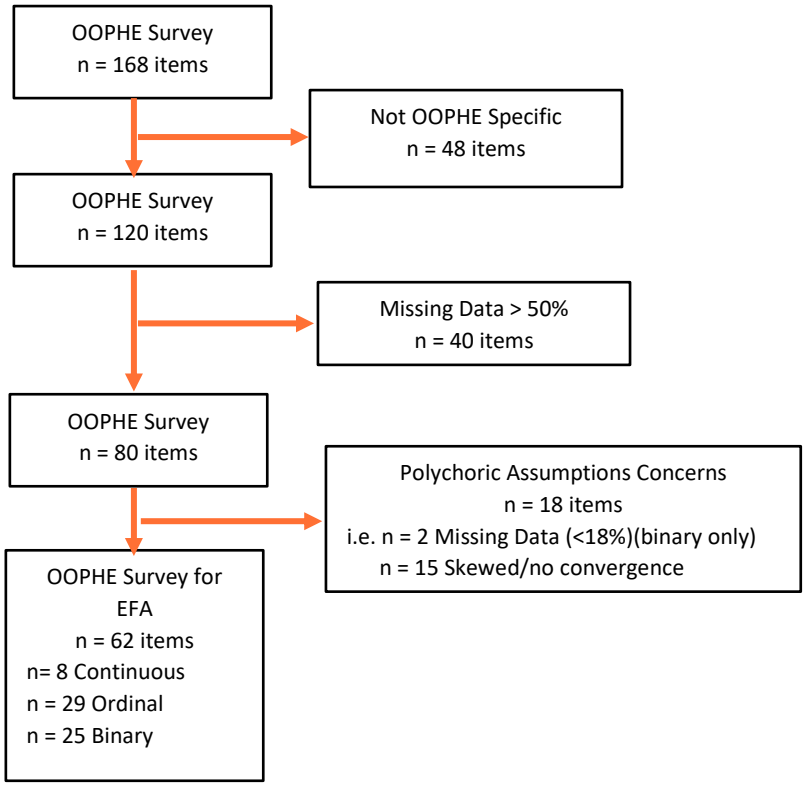
Does anyone who lives at your house receive any of the following [first_name]?

Age pension	◯ Yes ◯ No

Pensioner Card	◯ Yes ◯ No
Service Pension (DVA)	◯ Yes ◯ No
Disability Support Pension	◯ Yes ◯ No
Sickness Allowance	◯ Yes ◯ No
NewStart Allowance (unemployment benefit)	◯ Yes ◯ No
Carer Payment and/or Allowance	◯ Yes ◯ No
Abstudy	◯ Yes ◯ No
Childcare Benefit and/or Subsidy	◯ Yes ◯ No
Youth Allowance	◯ Yes ◯ No
Commonwealth Rent Assistance or other housing support	◯ Yes ◯ No
Other (such as Widow allowance, BasicsCard)?	◯ Yes ◯ No
If other what is it [first_name]?	_____
[first_name] what is your family's annual income before tax each year, from all sources (i.e government payments, superannuation, allowances, etc)	◯ Under $20,000 per year (Under $379 per week) ◯ $20,000-$29,999 per year ($380-$579 per week) ◯ $30,000-$39,999 per year ($580-$769 per week) ◯ $40,000-$49,999 per year ($770-$959 per week) ◯ $50,000-$59,999 per year ($960-$1,150 per week) ◯ 60,000-$69,999 per year ($1,150-$1,339 per week) ◯ $70,000-$79,999 per year ($1,340-$1,529 per week) ◯ $80,000-$89,999 per year ($1,530-$1,729 per week) ◯ $90,000-$99,999 per year ($1,730-$1,919 per week) ◯ $100,000 or more per year ($1,920 or more per week) ◯ Don't know ◯ I would rather not say
[first_name] do you have private health insurance?	◯ No ◯ Yes, we have been in our policy less than a year ◯ Yes, we have been in our policy 1-5 years ◯ Yes, we have been in our policy more than 5 years

Does your policy provide	◯ Hospital and Extras ◯ Extra cover only ◯ Hospital cover only ◯ Ambulance cover only ◯ Unsure
Have you had to use your private health insurance for treatment for your child's injury?	◯ Yes ◯ No
Given your current needs and financial responsibilities, how would you say you and your family are getting, as a results of your child's injury?	◯ Very comfortable ◯ Reasonable comfortable ◯ Just getting on ◯ Still recovering ◯ Poor ◯ Very poor
[first_name] is there anything else you want to add about the costs or financial impact of your child's injury, that is not covered in the questions above?	_____

Thank you [first_name] for completing survey 1. We will contact you in 2 weeks time to complete survey 2.

[first_name] if you need to contact us, please email Courtney Ryder on cryder@georgeinstitute.org.au

D.4 Item Refinement Diagram for EFA