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Is Anybody Listening? Stories from Australia's First Nations Families whose Children had Sustained a Burn Injury

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A thesis submitted to fulfil the requirements for a Doctor of Philosophy

under the supervision of Prof Elizabeth Sullivan and Prof Rebecca Ivers

Supervisors Statement

As the primary supervisor of Julieann Coombes' doctoral work, I certify that I consider her thesis suitable for examination.

30th March 2020
Professor Elizabeth Sullivan

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Certificate of Original Authorship

I, Julieann Coombes declare that this thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the school of Public Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise reference or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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Acknowledgements

First, I would like to acknowledge the traditional owners of my Country, the Australia's First Nations people. I pay my respects to the ancestors for the care of our land. I commit myself as a First Nations researcher to work in partnership with other First Nations people with cultural respect and cultural integrity for justice and self-determination and for better health outcomes for our children, families and communities. The art work below was painted by a mother whose small child was severely burnt and it was her story of her sons journey to healing and going back to home to community the trees were his bush medicine for the scars and the water meant healing. The mother has given me permission to use her story in art for my thesis.

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Figure 1. The Healing Dreaming Story by Christine Walsh

I would like to thank and pay my respect to the children and their families who have shared their personal journeys with me and contributed their knowledge to my thesis. Without their voices, I would not be able to complete this dissertation. As we yarned, we all learnt together, cried tears of sadness and joy together and shared our unique

love of our beautiful culture and Country. “Is Anybody Listening? Stories from Australia’s First Nations Families Whose Children Had Sustained a Burn Injury” began in March 2017 and I completed this dissertation in March 2020.

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Copy editing and proofreading support for this thesis has been provided by Kirsten Jakobsen, without whose amazing talent I would be still be working on. Kirsten, I want to acknowledge your invaluable and precious time you spent helping me birth my thesis. I acknowledge the beautiful art work for my title page “Maison Barnier baby in coolamon” drawn by Anna Grimes and *Artwork by Zachary Bennett-Brook, artist and owner of Saltwater Dreamtime, a Torres Strait Islander contemporary artist.*

Outcomes Arising from this Thesis

JC, ES, KH, TM, RI reviewed papers and had unanimous agreement as to which papers were to be included.

Publications arising from the research

Paper 1 (Chapter Three)	
Title	Walking together to create harmony in research.
Authors	**Coombes J**, Ryder C.
Journal	*Qualitative Research in Organizations and Management*
Status of publication	Published – 2019; epub 30 July, doi: 10.1108/QROM-07-2018-1657
Unique contribution to knowledge	Chapter Three: Methods paper. From 2017 I began my PhD and studying the barriers and/or facilitators to burn aftercare treatment for First Nations children under the age of 16 years. This paper aims to discuss how one's standpoint impacts how the research was conducted including design, analyses interpretation and dissemination of results. I designed the study and wrote the manuscript.
Paper 2 (Chapter Four)	
Title	Factors that impact access to ongoing health care for First Nation children with a chronic condition.
Authors	**Coombes J**, Hunter K, Mackean T, Holland AJ, Sullivan E, Ivers R.
Journal	*BMC Health Services Research*
Status of publication	Published - 2018;18(1):448, doi: 10.1186/s12913-018-3263-y
Unique contribution to knowledge	Chapter Four: Systematic literature review. Access to multidisciplinary healthcare services for First Nations children with a chronic condition is critical for the child's health and well-being. The objective of this systematic literature review is to identify the factors that impact access and ongoing care for First Nations children globally with a chronic condition. I designed the study,

	conducted the literature search, performed data extraction and analysis and wrote the manuscript.
Paper 3 (Chapter Six)	
Title	The Journey of Aftercare for Australia's First Nations Families Whose Child Had Sustained a Burn Injury
Authors	**Coombes J**, Hunter K, Mackean T, Sullivan E, Ivers R.
Journal	*BMC Health Services Research*
Status of publication	Published 2020 Dec;20(1):1-1 doi: BHSR-D-20-00587R3 .
Unique contribution to knowledge	Chapter Six: First results paper of the study. The journey of aftercare for a child and their family is unique to each family, yet all families experienced similar barriers such as racism, confusion, miscommunication and other barriers as discussed through the voices of the families highlighted in this chapter. I designed the study, conducted the literature search, and wrote the manuscript.
Paper 4 (Chapter Seven)	
Title	"They are worth their weight in gold": Families and clinicians' perspectives on the role of First Nations Health Workers in paediatric burn care in Australia
Authors	**Coombes J**, Hunter K, Mackean T, Sullivan E, Ivers R.
Journal	Public Health Research & Practice
Status of publication	Submitted, 13 October 2020
Unique contribution to knowledge	Chapter Seven: Second results paper of the study. This chapter brings together two subsets of data, one from myself and one from another colleague. This chapter focusses on the actual and perceived role of First Nations Health Workers in burn care from the perspective of family members, First Nations Health Workers and the multidisciplinary team members. Importantly, it emphasises the importance of including First Nations Health Workers in the ongoing and complex care that is part of burn aftercare. I designed the study, conducted

	the literature search, performed data extraction and analysis and wrote the manuscript.

Authorship Attribution Statement

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Oral presentations at conferences and seminars

1. **Coombes J,** Ivers RQ, Hunter K, Maclean T, Sullivan E. Australia's First Nation Children's need for Culturally Appropriate Burn After Care, *National Conference on American Indian and Alaska Native Injury and Violence Prevention,* Denver Colorado, USA July 23th-25th 2019

2. **Coombes J,** Ivers RQ, Hunter K, Maclean T, Sullivan E. Walking Together to Create Harmony in Research: A Methodological Approach to Indigenous Research, *Healing Our Spirit Worldwide – The Eighth Gathering,* International Convention Centre, Sydney Nov 2018

3. **Coombes J**, Ivers RQ, Hunter K, Maclean T, Sullivan E. Australia's First Nation Children's need for Culturally Appropriate Burn After Care, *The Australian & New Zealand Burn Association Annual Scientific Meeting, Brisbane Convention & Exhibition Centre, Australia*, October 2018.

4. **Coombes J**, Ivers RQ, Hunter K, Maclean T, Holland A. What factors impact access to ongoing health care for First Nation children after a burn injury*? Worldwide Universities Network (WUN): International Indigenous Research Network Approaching Research: Ethics, Protocols, Collaboration,* Australia, February 2016

5. **Coombes J**, Ivers RQ, Hunter K, Maclean T, Holland A. Australia's First Nation Children's need for Culturally Appropriate Burn After Care, International SBI CONGRESS, **American Burn Association** Hyatt Regency Miami, Florida, USA 29 August – 1st September 2016

6. **Coombes J**, Ivers RQ, Hunter K, Maclean T, Holland A. What factors impact access to ongoing health care for First Nation children after a burn injury? *Poche Centre for Indigenous Health: Indigenous Health Symposium,* Australia, May 2015

7. **Coombes J**, Ivers RQ, Hunter K, Maclean T, Holland A. What factors impact access to ongoing health care for First Nation children after a burn injury*? AIPN, 12th Australasian Injury Prevention and safety Promotion Conference,* Australia, Nov 2015

8. **Coombes J**, Ivers RQ, Hunter K, Maclean T, Holland A. What factors impact access to ongoing health care for First Nation children after a burn injury*? AIPN, 2nd Australian Injury Prevention Network Aboriginal and Torres Strait Islander Injury Seminar,* Australia, Nov 2014

Abstract

Background

Australia's First Nations children experience a higher prevalence of burn injury than other Australian children. Optimal recovery from burns is associated with access to ongoing specialised care from the multidisciplinary burn team. Despite being over-represented, there is no research that tells the story of burn aftercare from the perspective of families.

Aims and objectives

This thesis aimed to identify barriers and facilitators to burn aftercare for Australia's First Nations children who sustain serious burn injuries and to ensure the voices of First Nations people is privileged throughout.

The objectives were to: 1) document the barriers and facilitators to aftercare; 2) understand the extent to which these barriers contribute to poor health outcomes.; 3) help inform the development of clear and practical clinical guidelines; 4) identify culturally safe approaches to support families when accessing multidisciplinary teams in health services and community settings; and 5) to better understand what appropriate resources are needed to support families leaving the tertiary health system and improve access to burn aftercare.

Methods

My thesis is a strong representation for being true to Australia's First Nations voice, maintaining strong cultural connection through storytelling, yarning and Dadirri and bringing that to the fore. My standpoint, my identity and being true to myself as a First Nations woman laid the foundations for this body of work. It has been essential that my cultural integrity remains intact throughout my study as a PhD student and to stay strong in my culture, this I have been able to achieve.

My systematic review found there was nothing in burns care that privileged the voices of First Nations peoples in accessing ongoing burn care. For First Nations children with

a chronic condition, the review highlighted a lack of culturally appropriate services and difficulties related to travelling to services as key barriers in accessing ongoing care. This was the starting point in ensuring First Nations families in Australia had an opportunity to be heard throughout my study and my doctoral thesis.

Setting

Australian First Nations children and their families who had sustained a burn injury were asked to share their journey to recovery to better understand the barriers and/or facilitators to burn aftercare. Families were recruited from a larger study "Understanding burn injuries in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes"

Families were recruited from a larger study "Understanding burn injuries in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes". Two families were from urban areas and one from a remote area In South Australia. In Queensland, two families were from the city, two from an urban area, two were from a remote community, one family was from a very remote area and one family lived in the Torres Strait Islands. There were five families in New South Wales including two from urban areas, two from remote areas and one from a very remote area. Two families were included from the Northern Territory who both lived in remote areas.

Yarning was conducted in the family's home.

Yarning with families

Eighteen families, which included 59 individuals, were recruited and yarns were conducted in families' homes and communities using yarning and Dadirri as Indigenist research methodologies. Interviews were audio recorded and transcribed verbatim. Data was stored in NVivo10 software (2014, QSR International Pty Ltd). Each transcript was analysed by JC using thematic content analysis, within the Aboriginal ontological framework. The research process had a depth and intimacy of Indigenous knowledges rooted in all aspects of the research, from project development to sampling, data collection, data coding, data analysis and interpretation.

Emerging themes were established, and a short summary sent to the families with the themes highlighted on their transcripts. Eighteen of the families were called, 15 of whom were available to reflect and discuss the themes found in their transcripts by asking what these themes mean to them, what can be done to alleviate the barriers found, and what are the most important themes (barriers/facilitators) for the burn aftercare needed for their child. All names and places have been changed for the privacy of the families, however the content continues to honour the voices of the families. There was the possibility for me to mention the families' names and communities as I had their consent recorded to do so. Fear of naming hospitals was not expressed by families nor was there a fear of being treated differently. It did not matter if by chance medical staff did find out who they were because racism was already an issue and families' desire to be heard was stronger.

The role of First Nations Health Workers

I have been able to show that maintaining my Indigenous way of knowing, being and doing can be achieved and respected while working side by side with a non-First Nations champion and my co-author for chapter 7. Our datasets although very different and coming from two different sub-studies also highlight how two worlds can come together to strengthen the need for equitable health outcomes for First Nations people.

Results

Families' experiences in burn aftercare within health services in Australia comprised of significant barriers in accessing healthcare following their child's burn. Racism, distance to aftercare services, cost of transport and parking in hospital grounds for outpatient clinics and disconnection from family were some barriers that families voiced as central issues. However, there were also some clear facilitators such as the support of First Nations Health Workers and Liaison Officers. It was also found to be fundamental for First Nations families to have input into care received and clear and concise communication on the care that is needed for ongoing burn aftercare to be effective. Most barriers can be alleviated by First Nations Health Workers' support and involvement in the child's burn aftercare.

Conclusion

This thesis details how vital early interventions are, notably those that are clearly planned and enacted in a culturally appropriate and safe way. The development of culturally appropriate care plans with the involvement of families, First Nation Health workers would facilitate a coordinated pathway to accessing culturally safe ongoing burn care. Consideration of the needs and responsibilities of all involved in the burn aftercare, including the multidisciplinary team, the First Nations Health Workers, the family and the child would lead to improved access to and outcomes of burn aftercare.

Prologue

The crackling of the fire, the shuffling of sheep being penned away, the setting of the sun and the sound of little feet running from the river to dress for bed pronounced another night was drawing to a close. The coolness of the night was refreshing after the harsh heat of the day. Soon the drovers, the drover's hands, the cook and her children all gathered around the light of the fire to eat the main meal of the day.

I was born into a drover's family in 1960, life as a drover's granddaughter was one of hard work, blistering heat day in and day out, but it was a life of freedom from a structured civilisation.

Country was home, our home, for months at a time sleeping beneath the stars in a swag, rising early in the morning to pack up and move to our next Country either by horse or by old truck that carried all our supplies. The drovers and dogs moving the sheep onto the next watering hole. We always got into camp hours before the drovers; it was then that we played in the red dirt, jumping over the large bunches of burs swept together by the dry winds and dust storms.

The open plains and rivers were our playground – splashing in the cool water while the grownups set up our campsite for another night. We knew that each day would bring a new Country, a new river or watering hole; these were the best days of my life.

We never heard the words do not do this or that, we never had adults hovering over us or telling us no, and yet we knew our boundaries, we grew up knowing the dangers of harsh country life in New South Wales, Australia.

We would travel through Kamillaroi to Bundjalung, Wailwan, Gumbaynggir, and Wiradjuri, sometimes travelling as far south as Yorta Yorta Country, and in each Country, Elders would visit our campsites to eat and yarn with us.

It was a time of storytelling and learning for the children until they went to sleep to the sounds of adults yarning about where to find the next campsite and the needed water

holes for the sheep. I was fifteen when I spent my last night droving and my mother and father moved my siblings and myself to Sydney.

Fast forward thirteen years, my childhood, once cherished, now just a lingering memory while I watch people in crisp uniforms coming and going into small rooms; sterile, white walls encompassed us as I waited for someone to tell me how my baby was. Questions unanswered about the surgery my daughter was having left me in despair. Alone I carried this burden, with family so far away from this city hospital. Alone, silent tears fell from my eyes, it was then I prayed, “God, please help me save my baby”.

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Abbreviations

AIATSIS: Australian Institute of Aboriginal and Torres Strait Islander Studies:

AHEC: Australian Health Ethics Committee: a principal committee of NHMRC.

AH&MRC: Aboriginal Health and Medical Research Council

AHREC: Aboriginal Human Research Ethics Committee:

AHW: Aboriginal Health Workers

AHWP: Aboriginal and Torres Strait Islander Health Practitioner

ALO: Aboriginal Liaison Officers

ATSI: Aboriginal and Torres Strait Islander

CINAHL: Cumulative Index to Nursing and Allied Health Literature

DoCs: Department of Community Services

FNHW: First Nations Health Worker

HREC: Human Research Ethics Committee

MMAT: Mixed Method Appraisal Tool

MOC: The Mosaic Outpatient Clinic

NHMRC: National Health and Medical Research Council

National Statement: National Statement on Ethical Conduct in Human Research

OT: Occupational Therapist

PRISMA: Preferred reporting items for systematic reviews and meta-analysis

Glossary of terminology

Australian Aboriginal and Torres Strait Islander Peoples and communities each have their own traditional cultures with their own unique ways of expressing these. Australian Aboriginal and Torres Strait Islander people will identify with language groups and traditional Country or land from where their families are from (Behrendt, 2012).

The term 'Indigenous' in my thesis is used to describe First Nations people globally. As a Gumbaynggir woman with connection to Kamillaroi people, I am a First Nations woman from Australia, I will be using the term First Nations people as the original custodians of this land called Australia.

Community: For Aboriginal and/or Torres Strait Islander peoples a community is first and foremost about Country, extended family ties and shared experience. It is about interrelatedness and belonging. Aboriginal and/or Torres Strait Islander peoples may belong to more than one community. For example it can describe where they come from, where their family is or where they work (Dudgeon et al., 2010a).

Stolen generation: The Stolen Generations (also known as Stolen Children) were the children of Australian Aboriginal and Torres Strait Islander descent who were removed from their families by Australian Federal and State Government agencies and church missions, under acts of their respective parliaments (Barney and Mackinlay, 2010).

Country: When Aboriginal people use the English word 'Country' it is meant in a special way. For Aboriginal people culture, nature and land are all linked. Aboriginal communities have a cultural connection to the land, which is based on each community's distinct culture, traditions and laws (Townsend et al., 2009).

Kamillaroi: a member of a group of Australian Aboriginal peoples who are the original custodians of north-eastern New South Wales (alternative spellings include Kamilaroi, Gamillaroi, Gamilaraay).

Bundjalung: a member of a group of Australian Aboriginal peoples who are the original custodians of northern coastal area of New South Wales.

Wailwan: a member of a group of Australian Aboriginal peoples who are the original custodians of the central-western plains of New South Wales.

Gumbaynggir: a member of a group of Australian Aboriginal peoples who are the original custodians of the mid-North coast of New South Wales.

Wiradjuri: a member of a group of Australian Aboriginal peoples who are the original custodians scattered throughout central New South Wales.

Yorta Yorta: a member of a group of Australian Aboriginal peoples who are the original custodians from the junction of Goulburn in the Southern Tablelands of New South Wales, and Murray River in present-day northeast Victoria.

Coolamon Study: We named the larger study Understanding burn injuries in Aboriginal and Torres Strait Islander children **"**The Coolamon Study". Coolamons were traditionally used by First Nations women to carry water and fruits as well as to cradle babies and it is from this larger study that my smaller qualitative study comes from (Ivers et al., 2015a).

Classification of burns: Epidermal, superficial dermal, mid-dermal, deep dermal, full thickness, as per the Royal Children's Hospital Melbourne.

Serious burns: Critical or serious burns take more than 14 days to heal and will leave significant scarring. Scar tissue may limit mobility and functionality, but physical therapy may overcome these limitations. In some cases, additional surgery may be advisable to remove scar tissue and restore appearance, as per the Royal Children's Hospital Melbourne.

Aftercare: Healthcare offered a patient after discharge from a hospital or another healthcare facility. The patient may require a certain amount of medical or nursing attention for a health problem that no longer demands inpatient status, as per the Royal Children's Hospital Melbourne.

Aboriginal and Torres Strait Islander Health Workers: are crucial to improving health outcomes of Aboriginal and Torres Strait Islander people. They play a vital role in the primary healthcare workforce, providing clinical and primary care for individuals, families and community groups. Aboriginal and Torres Strait Islander Health Workers across Australia work in a variety of environments. Aboriginal and Torres Strait Islander Health Worker roles exist in metropolitan, regional and remote (https://vetnet.gov.au/Public%20Documents/HLT_Knowledge_Guide.pdf).

Aboriginal and Torres Strait Islander Health Practitioners: are registered with the Australian Health Practitioners Registration Agency (AHPRA). Aboriginal and Torres Strait Islander Health Practitioner is a protected title under section 113 of the National Law. The Certificate IV in Aboriginal and/or Torres Strait Islander Health Care (Practice) is the qualification for registration as an Aboriginal and/or Torres Strait Islander Health Practitioner (Health, 2018).

Aboriginal/Indigenous Liaison Officer: Aboriginal Liaison Officers (ALOs) are available to provide emotional, social and cultural support to Aboriginal and Torres Strait Islander patients and their families when they use the hospital. They can assist with access to healthcare services and aim to increase the cultural awareness and sensitivity of healthcare services to the distinct needs of Aboriginal and Torres Strait Islander families. Liaison Officers do not need any qualifications (Health, 2018).

Child: The term child in this thesis is defined from 0- 16 years of age.

Glossary references

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Chapter One: Introduction

1.1 My Journey as a First Nations Researcher

I am a Gumbaynggir woman through my great grandfather, with connections to Kamilaroi Country where I spent most of my childhood living in a small town in north west NSW, Australia.

I held negative views on researchers and blamed some of the injustices done to First Nations people on white institutions and what researchers told white institutions must be done to fix our communities and us. An example of historical accounts of research conducted and harmful to our people is the Bernier and Dorre Island lock hospitals which were places of imprisonment, exile, isolation, segregation and medical research experiments that were made possible by laws of exception(Meyer, 2009). Research in First Nations communities globally had become increasingly popular; communities were over-researched from the time of European settlement and colonisation, and the research conducted on Australia's First Nations peoples and communities continues today with little community engagement or impact on health" (Smith, 2013).

I applied for a position in a health institute never thinking for a moment that I would be successful in gaining the position, and not realising that I would one day soon become what I detested; a researcher.

Once I started working as a researcher, I realised that not all research has negative impacts on First Nations communities; such was the institute I worked for. I started working in a field very new to me and it took time to learn the new language of research, the jargon that was foreign to me. It didn't take long before I soon found myself enjoying the new direction I had taken as an Australian First Nations researcher.

I wanted to be part of a community which had a voice for the right to self-determination for First Nations people, but I first had to start by learning how this would become a reality as a First Nations researcher using Western methodologies. An opportunity through my employment led me to enrol in The University of Technology

in Sydney to obtain my Doctor of Philosophy in Public Health by research, although at the time I had not realised what I was signing up for or how much PhD students undertake during their studies.

During my initial theoretical class I learnt that there was a structure I needed to follow for my writing. There is a world of diverse methods, techniques and designs of methodologies in the field of social science, including both qualitative or quantitative approaches (Kothari, 2004). The need to develop an appropriate design as a First Nations researcher was evident, but quantitative research did not appeal to me so it was then I decided my work would be in qualitative research. Therefore, while looking for a framework for my research and wanting to take into account the need to be a vessel for Australia's First Nations people I decided not to use Western methodology. I chose to decolonise my research and use an Indigenous methodological approach, and so my literature review commenced and a new chapter of my life began (Russell-Mundine, 2012).

As an Aboriginal PhD candidate, I decided to conduct my research using Aboriginal ontology and epistemology as a framework, which is holistic, interconnected, person centred and grounded in Aboriginal ways of knowing and being as the foundation. I have written about my Indigenous methodological approach and standpoint in more detail in chapter three, Research Design and Methodology "Walking Together to Create Harmony in Research: A Murri Woman's Approach to Indigenous Research Methodology".

1.2 Introduction to burns in First Nations Children

Australia's First Nations children experience burns at least double the rate of other Australian children, constituting a high proportion of burns patients Hazard ratio of 2.4 times more than other Australian children. The hospitalisation rate for burn in injury for First Nations children compared to other Australian children is 4.8 per 10000 (Möller et al., 2016).

(Möller et al., 2014; Möller et al., 2017b; Duke et al., 2011a).

Studies in the general population have associated optimal burn outcomes with both access to comprehensive and ongoing burns care following discharge from hospital and the ability for patients to return to their pre-burn activities (Fraser et al., 2018). First Nations people experience enormous problems created by distance, remoteness and financial hardships which result in a high probability of the child and/or the family never fully recovering.

Ensuring that treatment and ongoing care is planned such that families are readily able to access appropriate care is an essential aspect of burns care, but it is unclear how well this occurs in the treatment of burns in Australia's First Nations children. Barriers to ongoing burn aftercare are due in part to the vastness of Australia. Although telehealth appears to be improving healthcare in remote areas, again, it is not known how this affects aftercare for children who had sustained a serious burn injury (Fraser et al., 2017). Despite being over-represented in burn injury hospitalisations, no studies have focused on the barriers and/or the enablers to culturally safe aftercare for Australia's First Nations children who have sustained a burn injury. The aim of this study was to identify barriers and/or facilitators to ongoing healthcare and well-being for Australia's First Nations children who sustain a serious burn, had been discharged from a burns ward and were now living back home in their communities. Learning and listening to what this means from the perspective of the child and their families highlights the importance of this study.

1.3 Understanding burn injuries in Aboriginal and Torres Strait Islander children

My project has contributed to the qualitative component of the larger NHMRC funded study being conducted by The George Institute for Global Health; "*Understanding burns in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes"* (Ivers et al., 2015a).

The larger study looks at the care received, cost related to the burn care, describes the relationship between care and functional outcome, and identify barriers and facilitators to receipt of appropriate care. The study has been developed to ensure concepts, wording and culturally appropriate methods of management are

appropriate, providing evidence of feasibility and ensuring appropriateness of methods for this larger study. The study is working in partnership with clinicians, policy makers, Aboriginal Health Services and the community to develop a 'blueprint' for reforming services which will ensure that Aboriginal and Torres Strait Islander children receive appropriate and cost-effective care. Participants were interviewed at baseline and 3, 6, 12 and 24 months afterward at each site in Australia. Clinical information on burns, and care received, has been extracted from the medical records. This is the first cohort study of its kind and is still in the last phase of clinical data collection. It was within this study that I was recruited for the research assistant position in New South Wales.

Australia's First Nations children under the age of 16 years who had sustained a burn injury and present to a tertiary paediatric burn unit were recruited from New South Wales, Queensland, South Australia and Northern Territory. Data collected from this study included sociodemographic information, out of pocket costs, functional outcome and measures of pain, itch and scarring. Health-related quality of life was measured using the PedsQL, and impact of injury using the family impact scale. Data from medical records was also collected. *(Ivers et al., 2015a) Within this larger study four sub-studies were conducted by students undertaking their PhDs.*

As burns treatment itself can often be very painful often needing extended treatment, it is unclear how well patients are supported with culturally appropriate and safe burn care either in the hospital, or once they leave the hospital setting. Burns units report regularly losing contact with Australians First Nation patients once discharged to communities. The accessibility of high-quality care to First Nations children, who represent a high proportion of burns patients, particularly those from regional and remote settings, is critically important, given the complexity of long term burn care, where access to appropriate treatment is essential to produce good long-term outcomes (D'Cruz et al., 2013). Exploring the barriers and/or facilitators for burn aftercare from the perspective of the child and family would help us understand what needs to be addressed in our health systems. The question to barriers and facilitators formed this sub study and has advised my PhD which is situated within the larger study.

Steering Committee

This larger study is overseen by an Australian First Nations Steering Committee which includes First Nations stakeholders and community members. I was the chairperson of this committee. I am a First Nations person and as the research assistant I recruited families at The Children's Hospital at Westmead in NSW.This study has the support from First Nations peak bodies throughout Australia from its inception.

The role of the Steering Committee

The steering committee ensured that there was appropriate First Nations involvement across all sites and at all levels of the project including the design, conduct and to assist in the translation of the research findings into policy and practice and the dissemination of project findings. It was imperative that the Steering Committee promoted and supported First Nations community engagement and provide advice on culturally safe recruitment of participants at all sites to maximise the effectiveness and success of the project. The Steering Committee was also to assist in any conflict resolution and the management of risks.

1.4 My Research question, research aims and research objectives

1.4.1 Pivotal questions

The questions that were pivotal to this thesis were:

1. What are the barriers and/or facilitators to accessing burn aftercare for Australia's First Nations children and their families?
2. How can the barriers to burn aftercare be addressed in our health systems through the perspectives of the families of a child who had sustained a burn injury?

1.4.2 Research aim

This project aims to empower the voices of Australia's First Nations families who require a multidisciplinary team for burn aftercare to inform clinical practices and to enhance the healing process.

1.4.3 Research objectives

1. Identify barriers to healthcare for Aboriginal and Torres Strait Islander children who sustain serious burn injuries, from the perspectives of the patient and their families;
2. Understand the extent to which these barriers contribute to poor health outcomes;
3. Help inform the development of clear and practical clinical guidelines, and a strategy for their use in health services and community settings;

1.5 Outline of thesis

Chapter One introduces the writer to the reader and provides the background and introduction to my thesis. It briefly gives an outline of the research design and explains what my question aimed to investigate, the aims of the project and the objectives

Chapter Two introducers the reader to the historical background to Australia' First Nations children's lifestyle before colonisation and the importance of culturally safe practices in our health systems.

Chapter Three is a published Methodology paper, *Walking Together to Create Harmony in Research: A Murri woman's approach to Indigenous Research Methodology.* This paper describes the importance as a Murri woman and researcher of why I used decolonising research methodology. It also sets the scene for the rest of the thesis.

Chapter Four is a published systematic literature review, *Factors that Impact Access to Ongoing Health Care for First Nations Children with a Chronic Condition.* This review identified the lack of knowledge around the barriers and/or facilitators for ongoing aftercare globally for First Nations children with chronic conditions.

Chapter Five is a chapter explaining the importance of researching in an ethical manner that advances the voices of Australia's First Nations people. It takes the reader step by step using the 14 principals from The Australian Government National Health

and Medical Research Council guidelines and how I kept my cultural integrity throughout the research project.

Chapter Six is the first results manuscript for this thesis and is a published manuscript in the (*BMC Health Services Research* Journal, *The Journey of Aftercare for Australia's First Nation Families whose Child Had Sustained a Burn Injury.* The strength of this paper are the voices of the families whose child had sustained a burn injury. It provides the perceptions of barriers and/or facilitators the families experienced while accessing burn aftercare.

Chapter Seven is the second results paper (submitted to *Burn Care and Research), "They are worth their weight in gold", families and clinicians' perspectives on the role of First Nations Health Workers in paediatric burn care in Australia.* This paper presents the importance of culturally safe healthcare using First Nations health workers as facilitators for ongoing burn aftercare.

Chapter Eight are the stories as told by the First Nations Families. Names, places and genders have been changed to protect the families otherwise it is the voices exactly as told by the families of their journeys, the heart ache and the resilience of the families whose child had sustained a serious burn injury.

Chapter Nine is the discussion chapter that ties all the chapters together and gives compelling recommendations for needed policy change in our health systems for equity and equality for Australia's First Nations children accessing burn aftercare.

Chapter Ten Is a personal note to the reader and explains my standpoint in more depth. My understanding from a non-research background through to the completion my thesis is also explained to help the reader understand why my thesis has been written in such a personal way.

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Chapter Two: Background

2.1 Culture and wellbeing

Before the British settlement there existed more than 600 nations in Australia cared for by First Nations people, and approximately one million First Nations people in total (Behrendt, 2012). These Nations were established and developed over 60,000 years while also adapting to environmental and landscape changes (Behrendt, 2012). Each nation spoke different languages and within these, different dialogues, and have diverse cultural beliefs, practices and traditions. Within these nations were clans, some were small family clans, others were larger, and each person within this complex family system knew and understood their kin and their land (Museum, 2018).

First Nations people traditionally use storytelling in different ways to teach children how they should behave and why they should behave in a certain way Knowledge was also passed on to children through creation stories called dreaming. Traditionally there were no written words, so most stories were passed down orally through the generations. Children would learn these dreaming stories and pass them down to the next generation and in doing so would keep First Nations dreaming and culture alive (Van den Berg, 2005).

First Nations people had strong connections to their land, and it provided not only food and shelter but also medicine. They were strong and healthy, not just leading lives as hunter and gatherers as some are led to believe(Gee et al., 2014).

These traditions were handed down and taught to children who learnt from their mothers, fathers, Aunties and Uncles. First Nations people were well adapted to their surroundings, be it living on the coastal regions, desert areas, riverbanks and tropical rainforest, just to name a few. There were also traditional healers that would use not only bush medicine but also smoke, fire and water to heal ailments (Oliver, 2013).

In Australia our Aboriginal Elders are highly respected Aboriginal people and are respected for their wisdom, cultural knowledge holders and services in community.

Age is not the sole determinant of whether someone is classified as an Elder in their community. Elders in our communities are referred to as 'Aunty' or 'Uncle' and may or may not be relatives(Warburton and Chambers, 2007).

Kinships define the roles and responsibilities of teaching and raising children who were raised by the extended family members in their community:

> *"All people with the same skin grouping as my mother are my mothers... They have the right, the same as my mother, to watch over me, to control what I'm doing, to make sure that I do the right thing. It's an extended family thing... It's a wonderful secure system."* Wadjularbinna Doomadgee, Gungalidda leader, Gulf of Carpentaria, 1996 (Museum, 2018).

Add in more here about what health and wellbeing means for Aboriginal communities

2.2 Community Controlled Health Services

First Nations Community Controlled Health Services are important in providing culturally appropriate primary care(Hunter et al., 2005; Campbell et al., 2018). There has been emphasis on prioritising First Nations people's access to culturally appropriate primary healthcare to maximise prevention opportunities for chronic conditions(Arabena and Moodie, 2011). Nonetheless, there have been studies highlighting the delays First Nations people experience accessing hospital care for a variety of health conditions *"suggestive of problems with the interface between primary care and the acute sector*" (Scrimgeour and Scrimgeour, 2008). Scrimgeour and Scrimgeour suggest here that there is a particular problem that relates to disconnect between services. Furthermore, there are also gaps in understanding what aftercare services First Nations people access once discharged from hospital, including how they access prescribed medications and dressings (Henderson et al., 2007).

2.3 Culturally safe aftercare

Australia's First Nations people concepts of health is holistic, and encompasses the mental, physical, cultural and spiritual health, of land or country and is central to the wellbeing of First Nations people and their community. In 1989 the National Aboriginal Health Strategy Working Party provided the following definition of 'health', Health is not just the physical wellbeing of the individual but the social, emotional and cultural wellbeing of the whole community(Service, 1989). This is a whole of life view and it also includes the cyclical concept of life-death-life.

between First Nations people and other Australians are acknowledged, papers and reports are recognised, valued and used in health institutions for the perceived betterment of First Nations people's health.

There is a lack of reference to First Nations Children and facilitators or barriers to aftercare of burn injuries within a policy context, both globally and at the national level. While there is no reference to burns aftercare specifically, there are many references to the rights of First Nations peoples to access a healthcare system free from racism and discrimination (UNDRIP, National Aboriginal and Torres Strait Islander Health Plan, National Framework for Continuous Quality Improvement in Primary Health Care for Aboriginal and Torres Strait Islander People). First Nations peoples globally welcomed the adoption of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) in 2007, and Australia signed on from 2009. Article 23 of the UNDRIP specifically states that, *"Indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions."*

Within Australia's National policy context, the National Aboriginal and Torres Strait Islander Health Plan has a vision that the Australian health system is free of racism and inequality and all Aboriginal and Torres Strait Islander people have access to health services that are effective, high quality, appropriate and affordable. The plan uses a human rights and social determinants approach that centres rights to culture and

wellbeing. There is no reference to burn injury among First Nations peoples and only one mention of injury prevention but not in relation to children.

The National Framework for Continuous Quality Improvement in Primary Health Care for Aboriginal and Torres Strat Islander people is a framework that was developed by the National Aboriginal Community Controlled Health Organisation in 2018 (x). The framework provides practical support for health care providers and policy makers to embed Continuous Quality Improvement (CQI) into primary health care for First Nations peoples. The framework speaks to the need for increased health equity, improved cultural safety and ensuring that high-quality, comprehensive primary health care services are appropriate for First Nations peoples (x).Any mention of children within the framework focussed predominantly on immunisation rates and improving weight related health, with no mention of burns or injury prevention.

Reports such as 'Close the Gap' (Australia, 2016)have been recognised by and acted on by governmental and non-governmental bodies but none of these reports resolve the dilemmas for First Nations children with a burn injury or the ravaging impacts burns have on the child or their families. In fact, follow up 10 years after the commencement of the initiative showed that very poor progress had been made and that the initiative is very far from achieving its goals. In 2020, the Closing the Gap targets were refreshed after many years of advocacy from First Nations communities and organisations to widen the focus. The Closing the Gap refresh now includes four "priority reform areas" and 16 new targets, however has been met with critique on the ability for communities to enact true self determination and lacks focus on structural reform needed to address racial disparities(Bond and Singh, 2020). The ripple effect from the moment of the burn injury and the after effect once patients return to their homes, families and communities, leaves the child and family without hope of ever returning to a life where wellbeing, good health, cultural happiness and safety was a typical way of life.

2.4 Colonisation and accessing burn aftercare

Colonisation has had a devastating impact on First Nations peoples globally (Smith, 2013; Liu and Alameda, 2011; Paradies, 2016). In Australia, First Nations people still struggle for survival, for equality and equity in health, education, housing, employment and the right to good health and wellbeing. Child removal, cultural and social dislocation, loss of community and family, mental health problems, and marginalisation from services such as health, education and child and family services continue to have a devastating effect on the well-being of First Nations people (Marmot, 2011a). Removal of whole communities from their homelands, displacement and loss of self-determination, culture, moiety systems and language are major contributors to the health problems now experienced by First Nations families(Gracey and King, 2009). These factors impact on their children and their children's children, with detrimental effects experienced over generations causing generational trauma (Watson et al., 2012).

It has been well documented that colonisation has had a devastating impact on First Nations people globally (Smith, 2013). The manifestations of these problems include alcohol and substance abuse, domestic violence, poverty, poor health outcomes and higher morbidity and mortality rates and high out-of-home care(Gracey and King, 2009). Although the many health disparities for First Nations children globally are well-documented, there are still very limited studies exploring solutions to this ongoing dilemma (Paradies, 2016).

These issues have a significant impact on the health and well-being of First Nations children (Woolley, 2009; Liu and Alameda, 2011). Although the many health disparities for First Nations children globally are well documented (Bramley et al., 2005; Dahhan et al., 2012a; Sarche and Spicer, 2008) (Chang and Singleton, 2016), there are very few studies exploring solutions to the ongoing dilemma for aftercare (Thomas et al., 2015). Disparities in access to tertiary and primary healthcare services for First Nations children have existed globally since colonisation (Sarche and Spicer, 2008). However, despite significant over-representation of First Nations children among child patients with a burn injury, there is no documented research exploring the factors that impact

access to the required on going primary healthcare once the child is discharged from a tertiary burns unit and has returned home.

First Nations children need the continuity of ongoing healthcare for all chronic condition. It is not well understood why ongoing healthcare does not exists for First Nations children with a burn injury and stating the obvious they are as much entitled to ongoing healthcare as anyone else in this country.

This continuity for First Nations children with a burn injury must encompass multidisciplinary service provision that is interrelated and working together to meet the ongoing needs for the child with a burn injury following discharge. Encompassing a range of services will meet the complex needs of their burn aftercare, and achieve optimal health and well-being outcomes (Woolley, 2009).

2.5 The search

When I began my studies there was very limited published research on burns in First Nations people, and what was available came from Western Australia (Duke et al., 2012a; Duke et al., 2011a; Wood et al., 2005a). This research focused largely on describing the burden using routinely collected data, but not addressing quality of life or the burden of burn injuries once the child returned to their community. One study between 1983 and 2008 showed that hospitalisation rates for burns in the First Nations population was 3.8 times (95% CI 3.6 –3.9) that of other Australian populations (Duke et al., 2012c).

Available burns research has addressed the effects of the depth of scarring, optimal dressings to use, psychological effects on children globally, and documented statistics of how many First Nations children compared to the number of other Australian children have sustained burns (Alaghehbandan et al., 2012; Blakeney et al., 1993; Kim et al., 2012). However, despite the significant overrepresentation of Australia's First Nations children in burn-related injury, there has been no research investigating the serious social, psychological or physical impacts caused by burn injuries on an Australia's First Nations child, their siblings, and their parents or families.

I have been fortunate to work as a First Nations researcher on a large study conducted through The George Institute for Global Health titled "*"Understanding burn injuries in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes"* also known as *"The Coolamon Study*" between 2014 -2019. This study has now produced rich data and published many papers addressing burns care in First Nations children in Australia (Fraser et al., 2018; Fraser et al., 2019; Fraser et al., 2017; Ivers et al., 2015a; Coombes and Ryder, 2019; Möller et al., 2014; Möller et al., 2017b; Ryder et al., 2019b; Ryder et al., 2019a).

2.6 The journey

This project is a platform for First Nations families who have experienced the horrific journey of having a child with a burn injury. Giving these families a voice to explain their own experiences in the process from the onset of the burn, through the healing process to a place of health and wellbeing is urgently needed.

2.6.1 Approach

The interviews for this study were conducted in families' homes and communities using yarning and Dadirri as Indigenous research methods which are further explored in my methods section in this thesis (West et al., 2012; Fredericks et al., 2011; Ungunmerr-Baumann, 2002; Bessarab and Ng'andu, 2010b). Oral communications, interconnectedness and cultural integrity play a role in Indigenous ways of knowing, being and doing the methods used in this research aimed to give voice to First Nations people (Martin and Mirraboopa, 2003b). Once emerging themes appeared, I called participants for their feedback on the themes that had emerged. This collaborative enquiry process involves cycles of reviewing data between the researcher and the participants, where all parties are working together. Using this cyclic method gives ownership of the story to the storyteller and empowers the voices of the families (Geia et al., 2013b).

2.7 Framework

I used Aboriginal ontology, a qualitative research approach, as the framework. The Aboriginal ontological framework is a holistic framework based on interconnectedness,

person-centred care and Aboriginal ways of being(Cochran et al., 2008). This framework is flexible and ensures First Nations people are given a voice (Martin and Mirraboopa, 2003a).

I purposefully chose to work within an Aboriginal ontological framework as a Frist Nations researcher, that allowed me to apply a decolonising lens to the research process. This framework allowed me to explore alternative modes of interpretation to western science, in order to come together in the spirit of hope and shared community (Denzin and Lincoln (2015). I talk more about this framework and my decolonising practice in Chapter 3.

My chosen theoretical underpinning to my PhD then naturally led me to using Indigenous methodologies within my data collection. The data was collected in 2017-2018 through yarning and Dadirri and were audio recorded and transcribed. The focus of the yarns related to the care received, and the barriers to care and treatment following a burn injury for Australia's First Nations children and their families. Eighteen First Nations children under 16 years of age (and their families), who presented at a tertiary burn unit following a burn injury, shared their stories and experiences. Included in the yarning were mothers, fathers, Aunties, cousins, grandparents and siblings in total 59 family members gathered together to share their stories. The methods I have used will be explained in more detail in subsequent chapters.

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Chapter Three: Research Design and Methodology

Walking Together to Create Harmony in Research: A Murri Woman's Approach to Indigenous Research Methodology

3.1 Preface

In the previous chapter I explored the background to First Nations health disparities and the need to use Indigenous methodologies when decolonising health research for First Nations people. In this chapter I will present the Indigenous research methods used. First Nations research has been documented and published by First Nations researchers globally using Indigenous methodology using various decolonising methods. Chapter three documents the methods I have used as a Murri woman and a PhD student navigating the academic system created by Western education while holding on to my cultural integrity, connection to culture and my spirituality. Strengthening my research through Indigenous methods included the consideration of guidelines that are culturally safe and appropriate to use when involving and reporting on First Nations people's health. In the absence of any frameworks or reporting guidelines that reflect the reporting of Indigenous research at the time of conducting my study or my analysis I have found that my study conforms to a recently developed guideline called the CONSIDER statement. The CONSIDER statement has provided a checklist for reporting of First Nations research which include:

1. Governance
2. Prioritization
3. Relationships
4. Methodologies
5. Participation

6. Capacity
7. Analysis and interpretation
8. Dissemination

This checklist aims to advance First Nations people and community health outcomes and was developed in collaboration with First Nations people in Australia (Aboriginal and Torres Strait Islanders), Canada (First Nations Peoples, Métis), Hawaii (Native Hawaiian), New Zealand (Māori), Taiwan (Taiwan Indigenous Tribes), United States of America (First Nations Peoples) and Northern Scandinavian countries (Sami)(Huria et al., 2019).

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3.2 Abstract

One's standpoint and consequent research paradigm impacts how we conduct research, including study design, analyses, interpretation and dissemination of results. In 2017, I began my PhD studying the potential barriers to aftercare treatment for Aboriginal and Torres Strait Islander children aged under 16 who had sustained a burn injury in one of five major hospitals in Australia. As an Aboriginal PhD candidate, I am conducting my research using Aboriginal ontology as a framework. My framework is based on a holistic framework with interconnectedness, person centred care and Aboriginal ways of knowing as the foundation. My framework has been shaped by my knowing, being and doing, and my worldview has informed and shaped my standpoint and the way my research has been developed and conducted. It is important for me to have a connectedness to each aspect of my research and to each individual person that shared their story: this was paramount to my ways of being. This connectedness stems from growing up on my Country and learning from my Elders, from my

connection to all entities living around, within and with me. Indigenous research methodology was used throughout the study, including yarning and Dadirri, a way of deep listening and learning, as the basis for interviewing.

Key words: Burns, Yarning, Dadirri, First Nation, child, aftercare.

3.3 Introduction

There are multiple studies examining the various aspects of burn injuries, from scarring depth, dressing management, psychological impacts, along with patient demographics, burn causation and global education and awareness programs developed on burns prevention (Parbhoo et al., 2010; Thomas et al., 1984; Turner et al., 2004). Nevertheless, for Australia's First Nations peoples no studies have examined burn aftercare in tertiary settings. I am conducting my research exploring the barriers and/or facilitators to ongoing care for Australia's First Nations children and their families and how they access that care once they have left the burns unit and are now living back in community. Burn injuries are complex and require long-standing, ongoing multidisciplinary care.

Cultural differences between Australia's First Nations people and other Australians are well acknowledged and many studies, papers and reports address these differences, and are used in health institutions in attempts to improve First Nations peoples' health. Reports such as The Close the Gap (Australia, 2016), Social Justice and Native Title Report (Commission, 2016), Stronger Futures (Commission, 2012) and others have been recognized and acted on by government and non-government bodies. However, it is clear that despite these reports there are still unresolved dilemmas, such as: lack of communication between service providers and families, cultural safety, distance from services that provide aftercare for burn patients, or the devastating consequences they have on the child and their families' health and wellbeing (Scullion, 2014; Fraser et al., 2018). Further, it appears through my study that very little has been achieved in connecting with the First Nations peoples voices, those who are in need of burns aftercare and are vulnerable in a healthcare system, where large population disparities still exist (Griffith et al., 2007; Durey et al., 2012).

Organisational responses to racism in healthcare require specific targeted approaches. Using Indigenous methodologies are a way of ensuring that change in our healthcare system occurs and is a response to the voices of Australia's First Nations people. Qualitative Indigenous methodologies in research are imperative in informing best practice delivery in health systems and healthcare organisations.

3.3.1 My story, my world view

> *"Although there are Indigenous groups all over the world, and although we are different in so many ways, the one thing that seems to bind us together is the common understanding of interconnectedness and that all things are dependent on each other."* (Steinhauer, 2002)

As a First Nation's Woman, and the first author of this article, to understand my research approach, it is essential that you understand where my identity comes from. My worldview comes from growing up on Country, a small remote Country in North West New South Wales Australia. My Grandfather was a drover, my father, an Aboriginal man, was the drovers' hand and my mother was the cook for all the workers. We spent more months moving sheep and cattle than we did living in town. Country was home, our home for months at a time sleeping beneath the stars in a swag, rising early in the morning to pack up and move to the next Country either by horse or by old truck that carried all our supplies. The drovers and dogs moved the sheep onto the next watering hole. We always arrived into camp hours before the drovers and it was then we played in the red dusty dirt jumping over the large bunches of burrs swept together by the dry winds and dust storms. The open plains and rivers were our playground splashing in the cool water while the grownups set up our campsite for another night. We knew that each day would bring a new Country, a new river or watering hole. These were the best days of my life.

As Children living on Country we never heard the words "don't do this or that"; we never had adults hovering over us or telling us "no" and yet we grew knowing our boundaries, we grew up knowing the dangers of harsh country life in Australia. We would travel through Kamillaroi to Bundjalung, Wailwan, Gumbaynggir, Wiradjuri

sometimes travelling as far south as Yorta Yorta Country and in each Country Elders would visit our campsites to eat and yarn with us. It was a time of storytelling and learning and deep listening "Dadirri" for the children until we went to sleep to the sounds of adults yarning about where to find the next campsite and the needed watering holes for the sheep.

I am now a mother of five daughters, two of whom were born with disabilities. These two special children spent months at a time in hospital settings throughout New South Wales.

My childhood once cherished quickly became a living memory, and stronger memories of watching people in crisp uniforms coming and going into small rooms, with sterile, white walls that encompassed us as I waited for someone to tell me how my baby was. Questions unanswered about the surgery my daughter was having left me in despair. Alone I carried this burden, with family so far away from the city hospital, alone silent tears fell from my eyes, it was at that moment that I become aware of what systemic racism felt like and the feeling of helplessness engulfed me. It was at this point that my passion for working in First Nations health was born. From here, I went onto become a nurse working in Aboriginal health.

My transition from nursing in First Nations people's health to researcher came from an opportunity to join the George Institute for Global Health in Australia on their study *"Understanding burn injuries in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes"* as a First Nations research assistant (Ivers et al., 2015a). This was the beginning of my journey into the world of research and academia**.** The burns units involved in this study were tertiary units in three Australian States and one Territory: The Children's Hospital at Westmead, Sydney, New South Wales, Queensland Children's Hospital (formerly Lady Cilento Children's Hospital), Brisbane, Queensland, Townsville University Hospital (formerly Townsville Hospital), Townsville, Queensland, Women's and Children's Hospital, Adelaide, South Australia and the Royal Darwin Hospital, Darwin, Northern Territory. In 2017, I enrolled in university and began my PhD studies, investigating potential barriers to burns

aftercare for Australian First Nations children under 16 who had sustained a burns injury and had left the care of burns units.

My worldview as a Murri woman, mother and a practicing nurse in the Aboriginal health sector has impacted my standpoint as a First Nations researcher and how I conduct my research. From the very outset of my research career, it was critical to keep my cultural integrity intact. I decided to conduct my research using Indigenous research methods, based on a holistic framework with interconnectedness, person centred care and Aboriginal ways of knowing as the foundation. To develop this, I had to fully understand and unpack my worldviews and how my identity as a Murri woman would impact and influence the data collection and the interpretation of the research. I have worked with CR, a First Nations colleague, to enhance my story telling and believe that CR has supported my journey into the world of academia writing. Working with CR assisted in facilitating my standpoint as Murri researcher, and influenced the study design including the yarning, analyses, interpretation and dissemination of results ensuring cultural integrity, respect and a connectedness to each family.

3.4 My journey and Indigenous research methods and methodologies

First Nations researchers are in a new era where many Indigenous scholars and researchers use Indigenous research methodologies to decolonise Western research and we, as First Nations researchers, are seeing the different ways in which Indigenous research methods can be developed. Shaun Wilson writes that to him research is a ceremony (Wilson, 2008), Roianne West writes about linking critical theory with reflective practice (West et al., 2012), Linda Tuhiwai Smith writes a strong case for decolonizing our methodology (Smith, 2013), Karen Martin comes from the perspective of knowing, being and doing but also taking into consideration that you need to knock before you enter any First Nations communities when doing research (Martin and Mirraboopa, 2003a; Martin, 2008). Indigenous methodologies are built from Indigenous knowledges and knowledge systems, which have always been in existence. We have always been researchers, but due to the perpetration of imperialism and power, we have not met the Western stereotyped perspective of what it is to be a researcher (Smith, 1999; Rigney, 1999). Indigenous methodologies are now

being recognised as imperative approaches to researching with First Nations peoples and communities (Rigney, 1999; Durie, 1998). Many First Nations scholars have pioneered the way and many more have developed their methods through their own worldviews and standpoints. Internationally recognised, they are distinguished scholars in their own research fields. Their work has been the foundation for Indigenous researchers globally, creating critical points in decolonising research methods to ensure quality, culturally safe health research and giving privilege to Indigenous voices globally (Lavallée, 2009; Rigney, 1999). As a First Nations researcher, my standpoint has informed and shaped the way my research has been developed and conducted. It is important for me to have a connection to each aspect of my research and to each individual person that shared their journey with me, this is paramount to my ways of being (Tur et al., 2010). This connection, I believe, stems from growing up on my Country and learning from my Elders, from my connection to all entities living around, within and with me. This framework is a holistic framework based on interconnectedness, person centred care and Aboriginal ways of knowing (Steinhauer, 2002). It is a flexible framework that ensures First Nations people are given a voice. Interconnectedness and cultural integrity play a part in the ways of my knowing and the methods used in this research aimed to give a voice to First Nations people by building a relationship of trust and communicating together, hearing each other and listening to the stories within their stories.

3.4.1 Yarning

Yarning is used as an Indigenous research method by many First Nations Researchers, in a variety of ways, such as social, research, therapeutic, and collaborative(Walker et al., 2014; Bessarab and Ng'andu, 2010a). It is very different from Western models of narrative inquiry. Yarning is a relaxed and informal conversation that is a part of First Nations culture, a way of introduction where we talk about our common family connections and where respect begins to grow, commonly referred to as family yarning (Walker et al., 2014). Listening to the drovers yarning about their day and the problems that needed addressing like the sheep with blowfly or fixing a part of the

fence they had just put up was yarning, sharing their insights and fixing problems together.

3.4.2 Deep Listening "Dadirri"

> *"To know me is to breathe with me, to breathe with me is to listen deeply, to listen deeply is to connect. It is a sound, the sound of deep calling to deep, down the deep inner springs inside us, we call on it and it calls on us"*
> Dadirri: A reflection by Miriam-Rose Ungunmerr Baumann (Ungunmerr-Baumann, 2002)

Dadirri comes from the Ngangikurungkurr people, of the Daly River in Northern Territory, Australia (West et al., 2012). Dadirri reflects the work of Aunty[1] Miriam-Rose, who explains the importance of Dadirri not only for First Nations people but also for other Australians (West et al., 2012). Dadirri is much more than just an informal discussion such as yarning, Dadirri is a form of deep listening. When the First Nations Elders of the community would come and sit by the fire and talk seriously there came a stillness around the camp. They talked about the storms rolling in or what track to take to reach the next watering hole safely, the drovers would listen deeply. It was this yarning and Dadirri that I used as Indigenous methods in my data collection phase (Geia et al., 2013a; Pearce et al., 2016). This approach is flexible and provides First Nations people with a voice that is heard and respected. It involves respecting culture, walking together, sharing stories and learning from one another and within this study, allowing Australia's First Nations families to tell their stories without the concern of misinterpretation (Atkinson, 2002).

[1] Australia's First Nations people traditionally refer to an Elder as Aunty or Uncle. This is an honorary term for an Elder who has gained recognition as a custodian of knowledge and lore also known to some as knowledge keepers. An Aunty by blood through our kinship is also acknowledged with love and respect. Here Aunty Miriam-Rose, is addressed as 'Aunty' as an Elder and knowledge keeper. The term Aunty is from the English language and is reflective of the colonisation of our people.

3.5 Overview of study

There is very limited published research on burns in Australia's First Nations children and no qualitative data on barriers or facilitators in accessing burn aftercare for Australia's First Nations children who have sustained a burn injury once they have left the burns unit. This study investigates the factors that affect access to culturally safe and appropriate burn aftercare for Australia's First Nations children. Participants were drawn from a larger longitudinal study, The Coolamon Study (Ivers et al., 2015b). Eighteen First Nations children and their families were invited to participate in this study *"Is Anybody Listening? Stories from Australia's First Nations Families Whose Children Had Sustained a Burn Injury."* The children, parents and families were asked about what services they have accessed since their discharge from hospital, the barriers and/or the facilitators to those services and what support services are available locally. Our preliminary findings found that the journey to recovery is unique to each child and their family depending on distance to health services, family dynamics and the experiences received from healthcare providers.

This research on the barriers and facilitators of accessing culturally appropriate burn aftercare in Australia's First Nations children will substantially improve the evidence base and influence culturally safe and appropriate burn aftercare. This in turn will lead to children who have sustained a burn injury to a place of recovery and wellbeing.

3.6 Ethical conduct

I submitted ethic applications to eight Human Research Ethics Committees (HRECs) and successfully obtained ethics approval from all eight HRECs. I also referred to the multiple relevant guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research, which were available to guide me through the research process (NHMRC 2003; AIATSIS 2013). I found these guidelines extremely helpful when working through the different ethics applications and also with other ethical issues presented by the larger Coolamon study such as the emotional distress on First Nations families.

Regular consultation with a First Nations supervisor and First Nations Researchers from the Coolamon steering committee also helped and guided the development and

implementation of all my research stages. I am grateful to have continuous support from First Nations Research Fellows and this has ensured that my research was conducted in an ethical and culturally appropriate manner.

3.7 Methods

3.7.1 Cyclical approach to analysis

After many discussions with First Nations researchers, colleagues and supervisors I decided to use a cyclical approach for my methodology. Using this cyclical approach safeguarded the research by being respectful and ethically correct from a First Nations person's perspective (Walker et al., 2014; Huria et al., 2019).

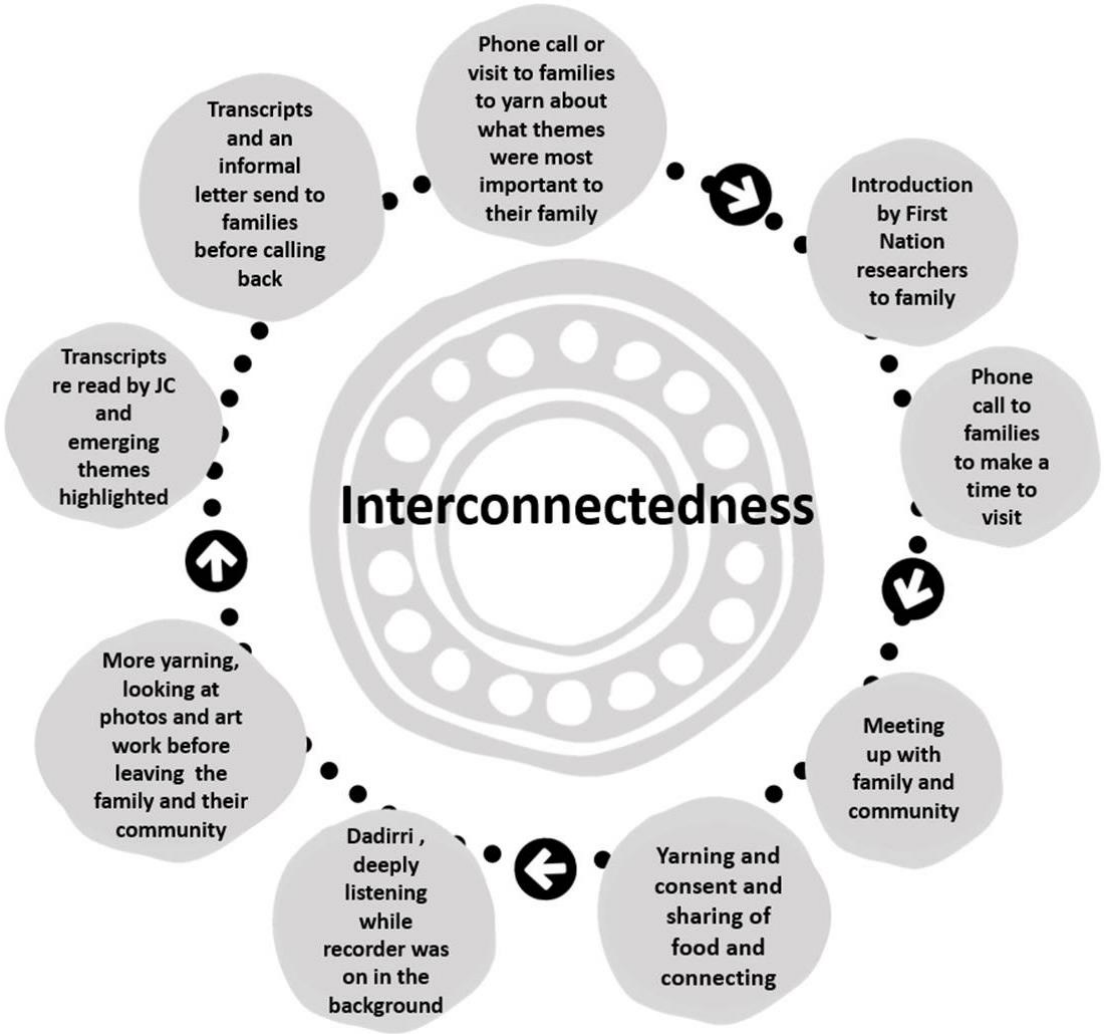

Figure 3.1: The Cyclic Phases

3.7.2 Yarning and Dadirri in action

For my research we would gather together in the family's home and in their community and use yarning and Dadirri as Indigenist research methods (West et al., 2012). We ate and yarned about our families and found that we had common connections and stories we could share. The children climbed on our laps as we yarned about the stories of our hospital stays and the confusion of not knowing what was supposed to happen next in the healing processes of our children. We yarned about the care our children received, the barriers to care and treatment needed for aftercare.

My intentions were not only about yarning and recording the stories of their burn aftercare for research purposes but also about connecting to their own personal burn aftercare journey. Using Dadirri to listen and hear what it was each family wanted to tell me and giving the time to deeply listen to the story teller, to truly hear what they wanted, helped me understand what each family had been through. I received visual support of their stories, photos of their communities or Country, a silhouette of themselves and their family members, artwork of their journey and family photos. The visual representation they felt happy about to support their story was discussed during our conversations and all families were happy to share what they had given me.

3.7.3 Connecting to people and their stories

The larger Coolamon study "Understanding burn injuries in Aboriginal and Torres Strait Islander children" employed First Nations researchers, including myself, in tertiary paediatric burns unit in New South Wales, Northern Territory, Queensland and South Australia. Trusting relationships were built over time between the researchers and the families of the child who had experienced a burn at each site. In keeping with Australia's First Nations protocols, the researchers at each site would approach families enrolled in the Coolamon study if they would like to take part in my study "Is anybody listening? Stories from Australia's First Nations Families whose children had sustained a burn injury." The families were given a culturally appropriate information sheet that was guided and developed by the Coolamon Aboriginal and Torres Strait Islander Reference Committee. The information sheet explained the reason why the

study was being conducted and by who. If the families were interested in the study and having a yarn with me the researchers from each site organised for the families and myself to meet at a time suitable for the families. The consent form was read aloud together with the families and then signed by each person in the room. The interviews for this study were conducted in the family's home and community using the reflexivity of yarning and Dadirri as an Indigenist research method (Coombes et al., 2018c). Oral communication, interconnectedness and cultural integrity play a critical role in Indigenous ways of knowing, and more specifically the methods used in this research, which aimed to give voice to First Nations peoples. All our communication was audio-reordered and then transcribed by a service based in Victoria, Australia. Reading the transcripts, I recalled the conversations I had with each family and themes from their stories emerged. A letter was written to the families with the themes developed from their transcripts. I asked the families to read their own transcripts as well as the letter that had the emerging themes written in dot points. I then called participants and yarned about the themes that had emerged and asked them what the most important themes to them were and if I had missed any issues they thought were more important. Using this cyclic method gave ownership of the story to the storyteller and empowered the voice of each family. Using Dadirri for the interviews with individuals or small family groups in each state elicited feelings and experiences about the care received and the barriers to care and treatment, including components of treatment prescribed for use in community settings, such as use of compression garments and creams that came from doctors.

Using this cyclic method is in line with Indigenous research methodology, gives ownership of the story to the story teller and empowers the voices of the families (Smith, 2013).

I have endeavoured to decolonise and reframe my research so that it meets the cultural needs and expectations of First Nations children and their families. The process of decolonisation in research requires ethically and culturally acceptable approaches. Decolonising research means working collaboratively with First Nations people, having research informed by First Nations people and allowing First Nations

people to direct how research outcomes are used to give voices to First Nations people and communities (Smith, 2013; Harvey, 2003).

3.8 Strengths and limitations for Indigenous methods

The strengths in my study have been the relationships that will last a lifetime. The healing that was created, for families through our ability to engage in the process of yarning and Dadirri to truly feel how these First Nations families were impacted. The time spent in interviews was also a strength as there were no time restraints, so spending a few hours or even days together cemented the connectedness that we had as researcher and expert knowledge holder and is also a core principle to the Dadirri process. The limitations to me as a First Nations researcher is not having the funding to continue visiting the amazing families that I now have a deep connection with, even though many call me I find it difficult not being able to visit when times are hard for the families. The connection built between the researcher and families using Indigenous research methods of yarning and Dadirri is a deep process that forms a different deep connection compared to other qualitative research processes, for me it is a natural Murri way of doing, way of being, part of who I am and my identity.

3.9 Conclusion

Working in Western academia, research and health structures while maintaining a strong cultural identity and community ties requires a continued connection to one's self knowing (Nakata, 2010). Using the reflexivity and multiple Indigenous methods in my research methodology has allowed me to continue to stay strong in my cultural integrity and identity (Wilson, 2014). It has afforded me the privilege of decolonising Western methodologies in my knowledge and study, upholding the sovereignty of First Nations people in the process.

We know there are still many disparities in the healthcare systems and to make a change we need to listen to those who have been through the processes. Using Dadirri as a methodological tool has given me the ability to listen deeply about the barriers First Nations people are confronted with in an open, honest and transparent way. Employing Dadirri was a useful method in discovering participants' barriers and/or

facilitators to accessing services. The stories will in the future help to improve the understanding of how a child with a serious burn and their family experience the journey to recovery (Coombes et al; forthcoming).

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Chapter Four: Systematic Review

Factors that Impact Access to Ongoing Health Care for First Nations Children with a Chronic Condition

4.1 Preface

Chapter three documented the methods I have used as a Murri woman navigating the academic system created by Western education while holding on to my cultural integrity, connection to culture and my spirituality. Chapter four is a systematic literature review that focused on First Nation's access to ongoing health care. Despite significant overrepresentation of Australia's First Nations children in burn-related injury, no research has investigated the barriers or facilitators in accessing a multidisciplinary team for burn aftercare or the serious negative impacts on the child, their siblings, and their parents or carers. How can a nation as rich as Australia sit back and watch as families are lost in a health system that is supposedly fair and just? Colonisation is well-known for the past injustices inflicted on our First Nations people, yet burn injuries occurring to our children and the associated effects on their families are having similar effects to those injustices, and once again, families are being ripped from one another, siblings are dislocated from family and communities because health and government systems do not know how to alleviate the devastating results of kinship dislocation on family culture.

Burns have been well studied, from examining the effects of the depth of scaring, optimal dressings to use, psychological effects on the child, and statistics of how many First Nations children compared to the number of other Australian children have sustained burns, and so on. There are multiple studies on burn causes, and educational programs have been developed around Australia on burn awareness and prevention. However, it appears no one has made the effort to listen to the voices of those who are lost in a system that caters to middle-class white Australian families; not only the

children who have sustained a burn, but also the families, siblings and communities distressed by the burn and its extended consequences.

Due to no peer reviewed published literature on Australia's First Nations children who had sustained a serious burn injury and needed ongoing healthcare at the time of writing my systematic literature review, a review was instead performed examining First Nations children globally with a chronic condition focusing on the barriers of accessing culturally safe and appropriate aftercare. This systematic literature review was performed to gain insight into the impact of culturally appropriate aftercare for children with a chronic condition and to identify gaps in existing knowledge to inform the aims of future study. A total of six studies from Australia, New Zealand and Canada were identified and included in this review.

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4.2 Abstract

Background: Access to multidisciplinary healthcare services for First Nations children with a chronic condition is critical for the child's health and well-being, but disparities and inequality in healthcare systems have been almost impossible to eradicate for First Nations people globally. The objective of this review is to identify the factors that impact access and ongoing care for First Nations children globally with a chronic condition.

Methods: An extensive systematic search was conducted of nine electronic databases to identify primary studies that explored factors affecting access to ongoing services for First Nations children with a chronic disease or injury. Due to the heterogeneity of included studies, the Mixed Method Appraisal Tool (MMAT) was used to assess study quality.

Results: A total of six studies from Australia, New Zealand and Canada were identified and included in this review. Four studies applied qualitative approaches using in-depth semi structured interviews, focus groups and community fora. Two of the six studies used quantitative approaches. Facilitators included the utilisation of First Nations liaison workers or First Nations Health workers. Key barriers that emerged included lack of culturally appropriate health care, distance, language and cultural barriers, racism, the lack of incorporation of First Nations workers in services, financial difficulties and transport issues.

Conclusion: There are few studies that have identified positive factors that facilitate access to health care for First Nations children. There is an urgent need to develop programs and processes to facilitate access to appropriate health care that are inclusive of the cultural needs of First Nations children.

Key words: Children, First Nation, Chronic condition, Healthcare, Access

4.3 Background

Shared histories of colonisation and disempowerment have had a devastating impact on health and social outcomes for First Nations peoples globally (Smith, 2012; Liu DM, 2011; Mussell et al., 2000; Anderson et al., 2016). First Nations people still struggle for survival, equality and equity in health, education, housing, employment and the right to good health and wellbeing (Mussell et al., 2000). The effect of Homelands being taken away, child removal, cultural and social dislocation together with the combined losses of culture, moiety systems and loss of language, contribute to marginalisation from services such as health, education and child and family services. This in turn can lead to a loss of self-determination (Marmot, 2011b) and other adverse outcomes, such as alcohol and substance abuse, domestic violence, poverty, poor health outcomes and higher mortality rates, high out-of-home care cases, high rates of incarceration and suicide (Reading, 2009; AIHW, 2015). These accumulated difficulties have had a significant impact on the health and well-being of First Nations children and their children's children for many generations (Woolley, 2009; Liu DM, 2011).

As a result, First Nations children globally are overrepresented in chronic conditions and injuries (Bramley et al., 2005; Dahhan et al., 2012a; Sarche and Spicer, 2008); (Chang and Singleton, 2016), including renal disease (White et al., 2010), respiratory diseases (Eley and Gorman, 2010 b), rheumatic fever, diabetes (AIHW, 2015), skin diseases (Clucas et al., 2008), unintentional injury (Ameratunga et al., 2010; Möller et al., 2015) and burns (Duke et al., 2011a; Sheridan et al., 2000; Alaghehbandan et al.).

Optimal recovery for such conditions is associated with ongoing access to culturally appropriate multi-disciplinary health services and health promotion resources (Baunach et al., 2012). However, disparities in terms of access to services delivered and outcomes for First Nations children remain (Sarche and Spicer, 2008; Mussell et al., 2000). Despite significant overrepresentation of First Nations children with long term chronic conditions including those because of an injury, little is known about factors that impact access to required ongoing health care once discharged from a tertiary health centre. A systematic review was carried out to examine factors (facilitators and barriers) that impact access to ongoing health care for First Nations children with a chronic health condition or injury.

4.4 Methods

4.4.1 Inclusion criteria

This literature review included global research studies published in English from 2000 to 2017. Publications were included if they reported primary research focusing on First Nations children, aged 0-16 years with a chronic condition, and their access to health care. Both quantitative and qualitative research designs were included (Table 4.1 shows search terms used).

To locate relevant studies two methods were used: (a) a search of data bases for primary papers from AIATSIS (Indigenous Studies Bibliography), CINAHL (The Cumulative Index to Nursing and Allied Health Literature), Rural and Remote Health Database, ATSI (Aboriginal and Torres strait Islander) Health Informit Online, Web of Science, Medline, PubMed, Cochrane Library and Australia Indigenous HealthInfoNet. (b) A hand search of references from identified studies (Table 4.2).

Table 4.1: Search terms used to identify relevant studies

	Age
1	Child*
2	Paediatric
3	Infant
	Population
4	Indigenous
5	Aborig*
6	Torres Strait Islander
7	Inuit
8	First Nation
9	Maori
10	Native American
11	Native
12	Sami
	Condition
13	Injury
14	Chronic condition*
15	Long-term conditions
16	Illness
17	Complex conditions
18	Injuries
19	Wounds
	Health care
20	Health care
21	Disparities
22	Community health services

Table 4.2: Databases searched by date and the number of possible relevant records corresponding to search terms

Date	Database	Records, n
25/03/2016	AIATSIS: Indigenous Studies Bibliography	0
25/03/2016	ATSIhealth	0
25/03/2016	Medline	24
28/03/2016	CINAHL	1
28/03/2016	Rural Data Base	0
28/03/2016	Health Info Net	0
29/03/2016	Lowitja	1
29/03/2016	Cochrane Library	4
29/03/2016	INFORMIT	1

4.4.2 Assessment of included papers

Papers were assessed for potential inclusion based on the abstract and title. For those papers that seemed appropriate the full text was accessed, and any duplicates removed. Full text papers were judged against the inclusion criteria. Included papers were summarised using a qualitative synthesis and were independently reviewed by two authors (JC and KH) with a unanimous agreement as to which papers were to be included. The quality of included studies was assessed using the Mixed Methods Appraisal Tool (MMAT) (Pace et al., 2012) (see Table 4.3 for details). The MMAT has previously been shown to be a comprehensive tool for assessing mixed method studies and meets the accepted standards for validity and reliability (Pluye et al., 2011; Mays et al., 2005). The MMAT tool has criteria for each study type and assigns an overall percentage ranking.

Scoring metrics

For each retained study, an overall quality score may be not informative (in comparison to a descriptive summary using MMAT criteria) but might be calculated using the MMAT. Since there are only a few criteria for each domain, the score can be presented using descriptors such as *, **, ***, and ****. For qualitative and

quantitative studies, this score can be the number of criteria met divided by four (scores varying from 25% (*) -one criterion met- to 100% (****) -all criteria met-). For mixed methods research studies, the premise is that the overall quality of a combination cannot exceed the quality of its weakest component. Thus, the overall quality score is the lowest score of the study components. The score is 25% (*) when QUAL=1 or QUAN=1 or MM=0; it is 50% (**) when QUAL=2 or QUAN=2 or MM=1; it is 75% (***) when QUAL=3 or QUAN=3 or MM=2; and it is 100% (****) when QUAL=4 and QUAN=4 and MM=3 (QUAL being the score of the qualitative component; QUAN the score of the quantitative component; and MM the score of the mixed methods component)(Pluye et al., 2011).

Table 4. Assessment of included papers (MMAT)

#	Author, Date, Country	Aims	Methods	Participants and setting	Analysis	Key findings	MMAT Scores
1	Michelle DiGiacomo 2013 Australia	To identify factors involved in accessing services and support for Aboriginal children with a disability	Community fora	Group 1: Parents and carers of Aboriginal children with a disability (5) Group 2: Health and social Service providers (17) Setting: ACCHS in metropolitan Sydney;	Framework analysis – consensus with co-authors and community members.	Both groups: Lack of awareness of services; Inadequate availability of services Carers: Racism; Insufficient or non-existent services; Providers: Logistical barriers; Cultural and historical issues impacting on effectiveness of services Suggested solutions: Need for an enhanced role of ACCHS and AHWs dedicated to support children with disability; school-based support; routinely updated information; Inter-sectoral partnerships	****

#	Author, Date, Country	Aims	Methods	Participants and setting	Analysis	Key findings	MMAT Scores
2	Rob Watson 2012 Unama'ki (Cape Breton), Nova Scotia, Canada	To Identify gaps in Asthma Education, Health promotion and Social Support for	Community based Participatory research	Group 1: Mi'kmaq parents and carers of youth with asthma Setting 1: Mi'Kmag communities Group 2: Mi'Kmag youth aged 8-12 yrs diagnosed with asthma. Setting 2: A 2-day camp.	All data collected from study was analysed by thematic framework	Both groups: There is a lack of support in the areas of social, educational and culturally appropriate resources. Barriers in accessing availability of services Suggested solutions: The need for involvement and collaboration with First Nations people for culturally appropriate support and educational resources for asthma education and intervention.	****
3	Shanthi Ameratunga 2010 New Zealand	To identify key issues and barriers to ongoing health care following hospitalisation for children who were admitted to hospital following unintentional injury:	A qualitative research design using Interviews and focus group	Group: In-depth individual interviews and 3 focus groups with 21 service providers' and families of children hospitalised with an injury. Setting: Health service departments.	Interviews were transcribed and data was analysed using a thematic framework	Key issues agreed on by both service providers and participating families included the inabilities to meet the needs of the children's emotional needs, lack of family support, lack of culturally appropriate resources, poor coordination of hospital and community health services and lack of aftercare follow ups. Suggested solutions:	***

#	Author, Date, Country	Aims	Methods	Participants and setting	Analysis	Key findings	MMAT Scores
						Ensuring culturally appropriate services are available and the need for cultural competency for service providers. Interventions to improve services at provider and patient levels, improvement in the development of clear concise discharge plans and the need to support families	
4	S.L. Thomas 2015 New South Wales, Australia	Investigating how to improve partnerships with services and First Nations families to maximize better health outcomes for First Nations children.	Semi-structured interviews and Focus Groups	Group 1: Focus Groups with community-based service providers. Group 2: Semi-structured interviews with service managers	Views of participants were documented and a thematic analysis was then used.	There is a need to improve paediatric outreach services for urban First Nations children through leadership, partnerships and culturally appropriate child health care based on a holistic model of care. Suggested solutions: Collaboration between health services and community members will improve access to services for First Nations children.	**

#	Author, Date, Country	Aims	Methods	Participants and setting	Analysis	Key findings	MMAT Scores
5	R.Cresp 2016 Western Australia	To determine whether a culturally appropriate program could improve attendance to out of hospital appointments	Quantitative evaluation	First Nations children aged 0-19 yrs who resided in Kimberley, Pibara or Perth regions	Pre-post de-identified data on hospital admissions, length of stay, emergency department presentations and outpatient appointments were used for the analysis	Findings suggest it is health outcomes for l children by engaging families with health services, improving communication between health service providers, and coordinating First Nations service provider led care.	****
6	R.Eley 2010 Victoria Australia	To give young First Nations people a knowledge and understanding of asthma and greater management over their asthma through a culturally safe and enjoyable process.	Quantitative measurement using medical reviews and spirometry and qualitative research using community based participatory research	First Nations young people aged between 5-17yrs	Study 1. Analysis of respiratory data were compared at different time intervals. Study 2. Interviews of participants were documented and a thematic analysis was also used	Study 1. There was an improvement in respiratory function. Study 2. The participants knowledge of asthma increased, asthma action plans were developed and there was greater compliance with medication. Other health benefits also achieved included the removal of barriers to accessing further medical services.	***

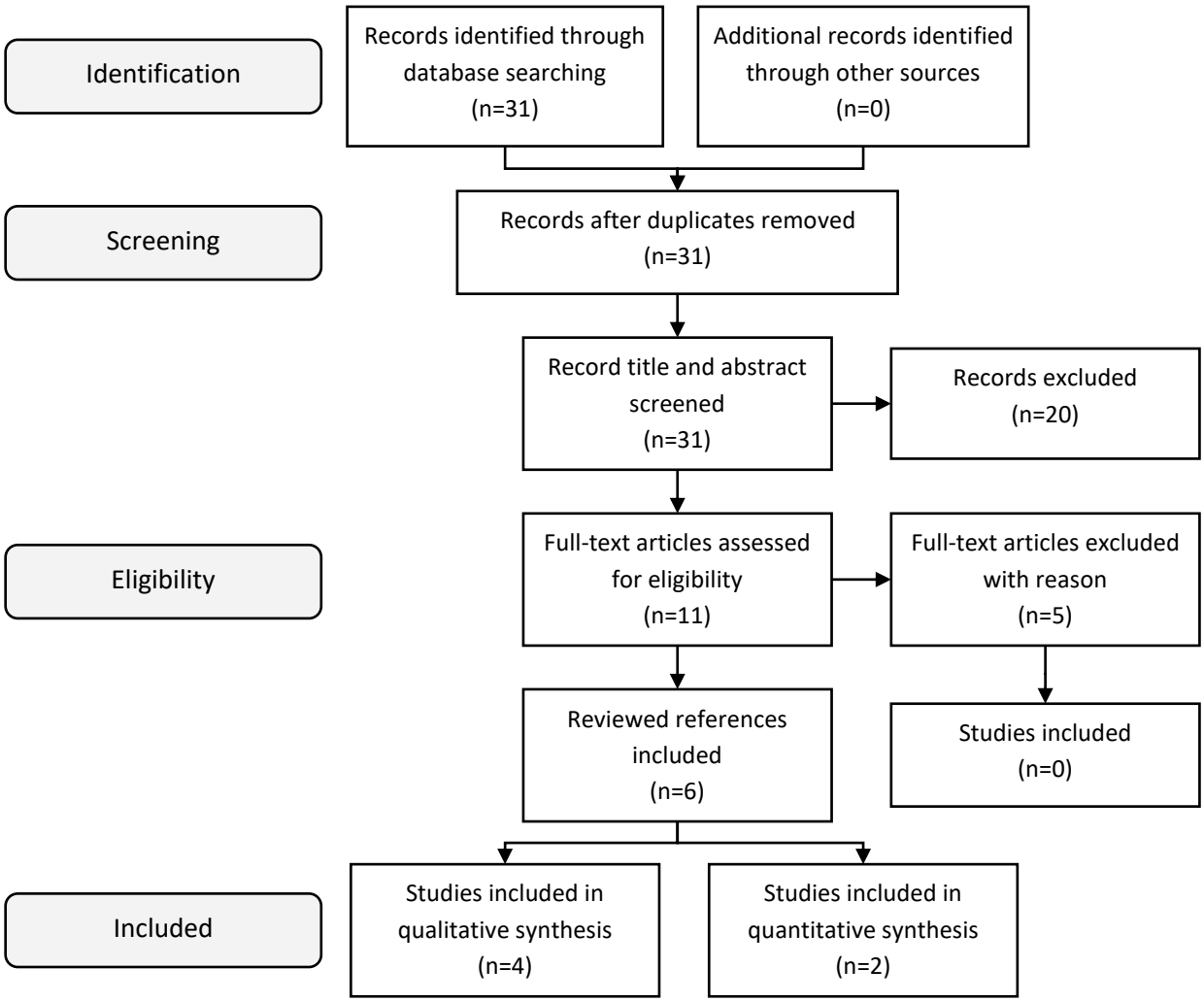

Figure 4.1: Prisma Flow Chart

This paper is reported in accordance with the PRISMA (preferred reporting items for systematic reviews and meta-analysis) reporting guidelines provided for systematic reviews and meta-analyses (Moher et al., 2009).

4.4.3 Ethics

All data were extracted from published manuscripts and therefore did not need ethics approval.

4.5 Results

The electronic database search returned 31 relevant records and no additional records were identified by a manual search of references. After assessing the records for relevance 11 reference citations were saved and full text was obtained and reviewed

for relevance to the research questions. From these articles, 6 met the inclusion criteria for the review. Of the six included studies, four studies were based in Australia (DiGiacomo et al., 2013; Thomas et al., 2015; Cresp et al., 2016; Eley et al., 2010), one from New Zealand (Ameratunga et al., 2010), and one from Canada (Watson, 2012) (See Figure 4.1 for results).

4.5.1 Included study methods and aims

For this review the definition of a chronic condition in children is a disease or illness that occurs in children between 0-16 years and has been present for more than 3 months or if the disease or illness has occurred more than 3 times in the past year, and includes major trauma caused from an injury (Mokkink et al., 2008; Boyse et al., 2012).

Four included studies reported results from qualitative research. Methods included the conduct of focus groups by Thomas *et al.* (Thomas et al., 2015), interviews by Ameratunga *et al.* (Ameratunga et al., 2010), the conduct of community fora by DiGiacomo *et al.* (DiGiacomo et al., 2013) and Watson *et al.* (Watson, 2012) incorporated a community based participatory research approach. One Australian study held focus groups in a Community Controlled Health Service to establish factors involved in accessing services for Australia's First Nations children with a disability (DiGiacomo et al., 2013). The second study from Australia used semi-structured interviews and focus groups with community based child health services and Service Managers to investigate the importance of partnership with First Nations families and health services (Thomas et al., 2015). The third study from Australia was a quantitative study by Cresp *et al.* (Cresp et al., 2016) which focused on pre-post de-identified data on hospital admissions, length of stay, emergency department presentations and outpatient appointments. The fourth study by Eley and Gorman (Eley and Gorman, 2010 b) from Australia included qualitative and quantitative methods

A study from New Zealand by Ameratunga *et al.* (Ameratunga et al., 2010) conducted interviews and focus groups to identify key issues and barriers to ongoing health care following hospitalisation for children who sustain an injury. A community based study from Canada conducted by Watson *et al.* (Watson, 2012) examined the support and

educational needs preferred by children with asthma by collecting data through participant observation, sharing circles and focus groups; these were conducted at a 2 day camp for children and carers. From these six studies, none mention the use of Indigenous research.

4.5.2 Quality of studies

The quality of included studies varied. Of the 4 studies one had a MMAT score of ** (50%) (Thomas et al., 2015), one study was scored at ***(75%) (Ameratunga et al., 2010) and two scored ****(100%). The two highest ranked studies included participatory research (Watson, 2012) with expressions from First Nations people as well as service providers (DiGiacomo et al., 2013). Using the MMAT tool resulted in an overall methodology score which was then calculated into a percentage (Pluye et al., 2011).

4.6 Facilitators to accessing health care

4.6.1 First Nations Health Work Force

Three studies from Australia presented evidence on how crucial the work of Aboriginal Health Workers is in partnership with community health services, in creating and maintaining culturally competent healthcare systems for First Nations children and their families (DiGiacomo et al., 2013; Thomas et al., 2015; Cresp et al., 2016). Aboriginal Health Workers and Aboriginal Liaison Workers (hereafter referred to as AHW and ALW) roles are diverse and some of their roles include, but are not limited to, communicating and facilitating access to other services, providing care that meets the social, physical, emotional and cultural needs to achieve better health outcomes for First Nations patients.

Another Australian study reported that non-attendance at appointments decreased among children who were involved in the Koorliny Moort program which consisted of a First Nations senior program manager, a First Nations senior social worker, two First Nations Liaison Officer (IRR, 0.83; 95% CI, 0.74e0.94; P<0.001) (Cresp et al., 2016). AHWs helped cultivate a trusting environment for First Nations children and families,

ensuring that First Nations peoples' holistic concepts of health and healing were respected (Thomas et al., 2015).

4.6.2 Community engagement

Studies from Australia also describe the importance of community engagement in accessing health services. It was reported that primary health community services working with AHW's played an integral role in cultivating a trusting environment helping to overcome cultural barriers (Cresp et al., 2016).

These studies also found that culturally appropriate child health services which collaborated with First Nations community organisations (Thomas et al., 2015; Cresp et al., 2016), First Nations families (Thomas et al., 2015; Cresp et al., 2016), First Nations Elders (Eley et al., 2010) and AHW who are local to that community (Eley et al., 2010) saw improved access to appropriate services (Thomas et al., 2015) (Eley et al., 2010). Another study found that cultivating relationships with communities created a culturally safe environment and reported families were more likely to drop-in for health care (Thomas et al., 2015).

4.7 Barriers to accessing health care

4.7.1 Transport and finance

Geographical locations due to remoteness and distance to services made it difficult for parents to bring their child in for appointments. Vehicles were not available to families due to low finance and public transport costs became a burden after multiple visits to clinics or other healthcare facilities (DiGiacomo et al., 2013).

4.7.2 Cultural competency

Lack of cultural competency in the service was also described as a barrier by Thomas *et al*. (Thomas et al., 2015), she describes the importance of implementing a culturally appropriate model of care based on trust and respect (Ameratunga et al., 2010; DiGiacomo et al., 2013); (Watson, 2012).

4.7.3 Language

Studies reported barriers due to language and promotional material not being culturally appropriate (Watson, 2012; DiGiacomo et al., 2013). The lack of interpreters was another reason why parents did not attend healthcare services with their children (Ameratunga et al., 2010).

4.7.4 Coordination

In Aotearoa, New Zealand a qualitative research study was conducted using in-depth individual interviews and focus groups with services providers who were involved with the care and support of First Nations children who had sustained an unintentional injury. A lack of coordination between hospital and community services were identified as barriers (Ameratunga et al., 2010).

4.7.5 Adequate follow up plans

Several studies reported the need for a clear, well developed follow-up plan, and that support systems for ongoing health care was imperative for First Nations children once they were discharged from the hospital to ensure best quality ongoing healthcare (Ameratunga et al., 2010; Cresp et al., 2016).

4.7.6 Fear of child removal

Long held beliefs and racism have a lingering impact on how health workers care for First Nations children and their families, with child protection services often being contacted (Ameratunga et al., 2010; DiGiacomo et al., 2013). This has cemented the fear of children being taken from families when attending healthcare services.

4.7.7 Staff turnover

High staff turnover has been globally problematic with medical and nursing staff seeing the child just once during the child's ongoing medical appointments. This leads to fractures in the continuity of healthcare (Thomas et al., 2015).

4.8 Discussion

First Nations children have a basic human right to the best possible culturally safe health care (Woolley, 2009; Sheppard and Hetherington, 2012). There have been many studies and research papers written about the burden of chronic conditions and injury in First Nations children (Economic, 2009; Möller et al., 2015; Sheppard and Hetherington, 2012; Alaghehbandan et al., 2010; Azzopardi et al., 2012; Duke et al., 2011a; Gunasekera et al., 2009; Watson, 2012; Webb et al., 2014; White et al., 2010). This review has found there is little previous work that addresses the factors that impact access to ongoing health care for First Nations children globally who have a chronic condition (Cresp et al., 2016). Western research is inevitably going to influence the interpretation of data from the non- Indigenous researcher due to imperial and colonial discourse (Smith, 2012). The included papers in this systematic review were written by researchers who have not mentioned the development of Indigenous research agendas, methodologies or protocols.

Being able to readily access appropriate health care is an essential aspect for all chronic conditions, but it is unclear how well this occurs for First Nations children. Ensuring that ongoing care is planned, culturally appropriate and inclusive of First Nations children and their family is paramount to maintaining and improving access.

The accessibility of high quality and effective ongoing care for First Nations children, who constitute a high proportion of patients with a chronic condition or injury, particularly those from regional and remote settings in Australia, New Zealand and Canada is particularly important given the complexity of their need for long term healthcare (Eades, 2004). Access to a holistic healthcare system that is culturally appropriate and culturally sensitive is essential to produce good long term health and wellbeing outcomes (Thomas et al., 2015; Ellison-Loschmann and Pearce, 2006). However, there is little evidence around what is most effective and most importantly what can facilitate that access. Notably, there were no studies identified for First Nations peoples of the United States, suggesting significant research gaps exist. (Economic, 2009; McBain-Rigg and Veitch, 2011). This review builds on what is known about barriers to accessing acute health care such as the transgenerational fears from

past treatment of First Nations people due to institutionalised racism from health service, the parent's fear of their child being removed from home by the welfare system and the lack of cultural sensitivity and awareness in healthcare services (AIHW, 2015; Woolley, 2009).

From this review, we also identified positive factors that facilitate access to health care for First Nations people. Studies have shown that First Nations health/liaison workers employed in health settings appear to alleviate some of the previously mentioned barriers and can be beneficial to better health outcomes (Chang et al., 2010; Dahhan et al., 2012a; Cresp et al., 2016) yet the lack of funding and resources in health institutions impedes on the hiring of First Nations staff (Ameratunga et al., 2010; Azzopardi et al., 2012; Bramley et al., 2005). There was clear acknowledgement of the need for First Nations health/liaison workers within healthcare centres. First Nations Health Workers have become instrumental in providing culturally appropriate health care and support for First Nations people in hospital settings and private clinics globally (Chang et al., 2010), which helps alleviate the impact of racism in such settings. Being able to talk to a health worker who understands culture improves a patient's understanding of the care and treatment needed for improved health outcomes. This in turn can reduce fear, mistrust and racism (Cresp et al., 2016).

In this review we found that having culturally competent health facilities was effective for First Nations people, and this is also evident from other studies examining other First Nations child health programs. In Western Australia, the Koorliny Moort program was designed specifically for Australia's First Nations children and also demonstrated the benefits of integrating First Nations Health Workers by engaging families with health services, improving communications and improved access to out of hospital health care (Cresp et al., 2016). There is also evidence that this approach is important for other marginalised populations.

One such example is a pilot study conducted by Dahhan *et al.* (2012b) in Amsterdam describing an approach called *The Mosaic Outpatient Clinic* (hereafter referred to as MOC). The MOC was set up in outpatient clinics at 3 hospitals in Amsterdam, specifically for Ethnic minority children who experienced chronic health issues such as

diabetes type 1, asthma and/or a metabolic disease. The aim of the MOC was to provide an insight into what bottlenecks prevent access to health services and better health outcomes for ethnic minority children who are socially disadvantaged. Although this study did not include First Nations children it did show that integrating student healthcare workers as cultural mediators that served at the patient-clinician interface to translate language and interpret cultural differences were identified as beneficial. Results of MOC trial showed that patients and families were more appreciative of services and had a greater insight to the child's chronic illness when the participants had access to a cultural mediator (Dahhan et al., 2012a). In addition, this review found that families and care providers reported the lack of culturally appropriate health information materials impacted their access to services. Such materials could be seen as interesting, informative and can improve quality of life (Watson, 2012). Community produced health messages with designs and images that reflect their community's culture would be more appealing to engage with. Involving community members in the development would also contribute to the cultural relevance of health related material (Watson, 2012; Baunach et al., 2012).

4.8.1 Strengths and limitations

There is difficulty in ascertaining the exact factors that impact access to ongoing health care for First Nations children globally due to the limited previous research. There are many limitations and biases to the evidence that currently exists such as cultural appropriateness of the studies and also the use of Western methodology versus the use of Indigenous methodology and the different views of First Nations concept of health and well-being to Western views of health (2009; Smith, 2012; Holmes et al., 2002; Mussell et al., 2000).

A strength of this systematic review was that it was led by a First Nations researcher, ensuring the included studies were viewed through the lens of a First Nations perspective using an interface method (Durie, 2004).

4.9 Conclusion

First Nations people are one of the most researched populations in the world (Smith, 1999). Despite this, the existing health disparities and unavailability of culturally appropriate and inclusive healthcare services are still evident today (Woolley, 2009; Chang and Singleton, 2016). Studies of First Nations children with a chronic condition, have typically been conducted using Western paradigms based on Western philosophies and Western concepts of health (2009; Smith, 2012; Holmes et al., 2002). As claimed by First Nations researchers in Australia and New Zealand the use of a Western framework to interpret Indigenous knowledge is oppressive. Western frameworks are limiting because they often fail to capture the complexities of Indigenous ways of knowing, potentially simplifying important cultural concepts and constructs (Russell-Mundine, 2012). Although this review found few studies examining factors impacting on access to ongoing health care for First Nations children, several themes emerged from the studies that were identified. These included barriers such as racism in health services, linguistic, lack of cultural appropriate health promotional material, and lack of cultural understanding from service providers. In conclusion, this review demonstrates that by understanding diversity and cultural background, service providers can deliver culturally competent care within health services. Also, appropriate levels of funding to support culturally safe healthcare services that support Aboriginal Health Workers, Aboriginal Liaison Workers, transport and finance will assist in ensuring ongoing access for First Nations children with a chronic condition.

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Chapter Five: Ethics, Integrity and My Research

> *"'Ethical conduct' literally means simply doing the right thing, but in reality, it means more. It involves acting in the right spirit, out of an abiding respect and concern for one's fellow creatures."* (Mandal et al., 2011; Council, 2018)

5.1 Introduction

In the previous chapter I found no research has investigated the barriers or facilitators of access to multidisciplinary burn aftercare or the serious ongoing negative impacts of burn injury on the child, their siblings, and their parents or carers. In Chapter five I present how I as a First Nations researcher conducted my research in an ethically appropriate manner.

Relationships and reciprocity were paramount in the privileging of First Nations peoples' voices in my projects design and during the conduct of the research. Ensuring that ethical standards were met, I began the journey of gaining approval from eight Human Research Ethics Committees (HRECs); it was exhausting but rewarding. Working within the eight HRECs' guidelines was at first daunting, until I was directed to the relevant guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research at the National Health and Medical Research Council (NHMRC) updated in 2018 (Council, 2018) and the guidelines from the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) for ethical research in Indigenous studies (Australian Institute of Aboriginal and Torres Strait Islander Studies AIATSIS, 2012). Since the introduction of these guidelines Australia has seen an increase in decolonising research practices and partnerships, where First Nations people have been given a voice and are being heard, and finally other Australian people and organisations are realising that First Nations people have the right to self-determination (Rigney, 2001).

I had regular consultation and continued support from a First Nations supervisor, and First Nations researchers also guided the development and implementation of all

stages in my research, ensuring it was conducted in an ethical and culturally appropriate manner.

Approval was granted by ethics committees in each state research was undertaken, as well as all the relevant Aboriginal health ethics departments. These include the Aboriginal Health Research Ethics Committee (South Australia; EC00185), Aboriginal Health & Medical Research Council Ethics Committee (New South Wales; EC00342), Human Research Ethics Committee for the Northern Territory Department of Health and Menzies School of Health Research (EC00153), Central Australian Human Research Ethics Committee (Northern Territory; EC00155), Women's and Children's Health Network Human Research Ethics Committee (South Australia; EC00197), Sydney Children's Hospitals Network Human Research Ethics Committee (New South Wales; EC00130), The University of Queensland Medical Research Ethics Committee (EC00179), Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (EC00175), Townsville Hospital and Health Service Human Research Ethics Committee (Queensland; EC00183).

5.2 Ethics in practice

The AIATSIS guidelines were first published in 2002 and the latest edition published in 2012. The guidelines have six categories that make principles for working with Australia's First Nations people and communities, these are:

1. Rights, respect and recognition
2. Negotiation, consultation, agreement and mutual understanding
3. Participation, collaboration and partnership
4. Benefits, outcomes and giving back
5. Managing research; use, storage and access
6. Reporting and compliance

The Australian Government NHMRC guidelines consist of six core values adapted from the 2005 guidelines "Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics" (NHMRC, 2005; 2018) and are

used for AH&MRC ethics applications, hence the reason for using them in this chapter, these are:

1. Spirit and integrity
2. Cultural continuity
3. Equity
4. Reciprocity
5. Respect
6. Responsibility

5.3 Connection

Each principle connects to the next principle and without the connection between all principles or core values, ethical research for First Nations people would once again be without integrity. Fundamentally, without consideration of each core value, colonisation would once again dominate. Undeniable connection exists between spirit, culture, equity, reciprocity, respect and responsibility - between land, Country, sky, water, animals, man, woman, child and nature. Staying true to my standpoint I used the six NHMRC core values to connect to the families who were both participants and equal partners in this research project on burn aftercare. To understand how these core values were used in this research methodology I will go through each with examples of how I, as researcher, and the family connected through narrative description.

5.3.1 Spirit and integrity

> *"Spirit and integrity is the central core value that binds all the other five values together. The first part, spirit, is about the ongoing connection and continuity between Aboriginal and Torres Strait Islander Peoples' past, current and future generations. The second part, integrity, is about the respectful and honourable behaviours that hold Aboriginal and Torres Strait Islander values and cultures together"* (Council, 2018)

The process began in the hospital wards where the research assistant who already had a connection through the larger Coolamon study with the family would introduce me

to the parent/parents or carer and I would introduce myself firstly as a Gumbaynggir woman, then by name, then as an Aboriginal researcher. I would wait for as long as it took for the right moment to explain the study, and when the timing was right, I would then ask if they would like to be involved in the study. Parents/carers were vulnerable and at a chaotic time in their life, therefore respect for their feelings was the most important issue at that moment, not the consent form. Sometimes it would take days before the parent/carer had the time to discuss the study and read all the information I had given them before the consent form was signed, but the families were always happy to help in any way they could.

Connecting with the parent or carer was the beginning of connecting with family and later after leaving the hospital, connecting with their community. Travelling to the families' communities and homes to collect the data they had given consent for was exciting and daunting at the same time. There was never any need to be concerned as they all welcomed me into their homes and introduced me to other family members who were there.

We would sit for hours, sometimes no words were spoken but while we sat beside the child or outside the operating theatre with the family, a connection grew. We knew our connection from the past and our connection that was current meant respect existed between us, we knew our connections would last into the future. There were moments of talking about family and connections we had through our mothers' or fathers' lines, laughter when we told a funny story of someone we knew. Sometimes there were tears and all we could do was wait in silence until the baby settled and the pain relief had worked until we could yarn some more.

5.3.2 Cultural continuity

> *"Cultural continuity contributes to a sense of strong, shared and enduring individual and collective identities. Cultural continuity includes maintaining the bonds and relationships between people and between people and their environment. It also includes responsibilities in respect of spiritual domains. Aboriginal and Torres Strait Islander Peoples continue to preserve their*

cultures and identity by reflecting on and drawing strength from their individual and collective identities" (Council, 2018).

Travelling to communities that I did not belong to meant I needed to respect their Country and their Country's customs which I did by respecting and learning from the family's knowledge. As is custom in our culture, I bought gifts or food to share as we yarned about the burn injury and the aftercare the child and family were receiving or had received (Dudgeon et al., 2010b). We first discussed the reason for the study and confirmed that the consent form signed was informed consent. We spent as much time as needed to ensure the parent/carer and family members understood that connection, culture, transparency, and integrity were foremost in this study and their decision to share their journey was a chance to have their voices heard. As children were still undergoing burn aftercare, it was made very clear that if families decided not to continue with the study that it would not impact the child's care in any way.

Due to the strong connection that continued to grow between us, parents and families wanted to talk of their child's aftercare and the concerns they had not only for the future of the child but also that of the family. There was a strength in their voices about what the systems needed to do, and together we were able to identify issues we both had and realise that we had similar experiences with our children's aftercare, yet we respected each other knowing our journeys were different. Their search for knowledge and to understand what can be done to improve the aftercare for their child who had sustained a serious burn but no longer had the ongoing support of an inpatient was the reason they chose to tell their story.

Respect for the family was an important factor and it was evident to the families that I would stand by my cultural integrity and preserve their views and voices. Each family become a partner in the research study from inception, to analysing their own transcripts and to dissemination of findings.

5.3.3 Equity

"Equity is reflected by a commitment to showing fairness and justice that enables Aboriginal and Torres Strait Islander Peoples' culture, history and

status to be appreciated and respected. Many instances of discrimination and marginalisation have resulted in multiple inequities for Aboriginal and Torres Strait Islander Peoples and communities. In research, Aboriginal and Torres Strait Islander Peoples have perceived the distribution of benefits from research as flowing mostly to the researchers and research institutions." (Council, 2018)

Throughout this study my aim was always to ensure that the voices of the child and the family was at the centre of my research. While I was a research assistant for the larger project *"*Understanding burn injuries in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes*",* I hypothesised that there was a need for improved support during burn aftercare. The more I listened, the more families voiced their concerns about their child's aftercare and the family's ability to manage the long recovery road ahead. This study has always had First Nations people's equity in research in the forefront. Hence the inequities mentioned in this thesis are those raised by the voices and the journeys of individual families who have all been a partner in the research voyage. Families spoke about the discrimination and racism they felt when they attended the clinics for their child's burn aftercare, and they feared that being a partner in research could be detrimental to their family. They spoke of the real fear of having their children removed by child services. Respect and appreciation for each family as partners in this research meant that they were the voices that were empowered to speak out about the inequity of the healthcare they had received, and instead of being marginalised in research, here they were empowered.

5.3.4 Reciprocity

"Aboriginal and Torres Strait Islander Peoples' way of shared responsibility and obligation is based on their kinship networks. This process keeps Aboriginal and Torres Strait Islander Peoples' ways of living and family relationships strong. These responsibilities also extend to caring for Country, which includes the land, sea, waterways, animals, biodiversity and ecosystems and involves sharing benefits from the land, sea and waterways; redistribution of resources; and sharing food and housing.

> *Reciprocity should enable agreements where all groups or people have equal rights and power in relationships, although in the context of research this often involves unequal power relationships. Reciprocity recognises all partners' contributions, and ensures the benefits from research outcomes are equitable and of value for Aboriginal and Torres Strait Islander people and communities."* (Council, 2018)

My research question was relevant to the families involved, and reports on the inequities, barriers and facilitators identified by the families in accessing the multidisciplinary teams for burn aftercare.

While discussing the research project and my PhD at the beginning of yarning together, families were assured that the child's and family's priorities would be in the forefront of any publication or presentation developed that involved their story. This was achieved using a cyclical approach where all families were partners in analysing their own data; this is covered in more detail in Chapter 3 (Coombes and Ryder, 2019). Newsletters that included posters that had been presented were mailed out, and each family was asked before any paper was finalised if they would like to have the paper, written by myself, sent to them either by post or email.

The importance of identifying and mitigating unwanted impacts for the family was dealt with from the start, ensuring all participants were unidentifiable by changing names, places, sex of the child and family demographics. As First Nations communities are small and only five hospitals were involved in the study, the families' priority was that the child and their family be safe from any repercussions of telling their stories from child removal agencies or further racism while being treated in the burn clinic. Working together as partners in this research project, families expressed a hope that their voices would improve access and quality to burn aftercare for future children who sustain a burn injury.

5.3.5 Respect

> *"Respect is expressed as having regard for the welfare, rights, knowledge, skills, beliefs, perceptions, customs and cultural heritage (both individual*

and collective) of people involved in research. Within Aboriginal and Torres Strait Islander cultures, respect is reinforced through, and in turn strengthens, dignity. A respectful relationship promotes trust and co-operation." (Council, 2018)

As a Gumbaynggir First Nations woman I was determined that my research was always going to respect and honour culture; this was not always easy when working in the world of academia and research, but my cultural integrity never failed to fight for what I believed was right for First Nations people and communities. As stated throughout my thesis, the voices of the child and family were important in forming this research. Using Indigenous methods reinforced respectful relationships with all children and families involved in the research.

Yarning with each family about the research meant talking, listening and learning from individual families. Each family belonged to different communities and had their own cultural customs, this was instinctively respected by me as a First Nations person from outside their community, however through yarning together we were able to connect, respect and value each other for who we were and for which community we come from. The connection that we developed, along with yarning and Dadirri, bought with it a trust and an openness where mothers, fathers, children, Aunts, Uncles and other family members confidently shared their journeys with me (Geia et al., 2013b; Coombes et al., 2018c).

5.3.6 Responsibility

"Central to Aboriginal and Torres Strait Islander societies and cultures is the recognition of core responsibilities. These responsibilities include caring for Country, kinship bonds, caring for others and the maintenance of harmony and balance within and between the physical and spiritual realms. A key responsibility within this framework is to do no harm, including avoiding having an adverse impact on the ability of others to comply with their responsibilities. Also, an individual's responsibilities are not limited to them alone and may relate to the accountability of others. Responsibilities may

be shared with others so that as a group they will also be held accountable" (Council, 2018)

Respect for kinship bonds in my research was important for me, to hear all the voices in the child's healing journey and to fully understand how barriers or facilitators affected not just the child's journey but the families as well. Therefore, all family members with responsibility to the child were invited to be part of the research. Yarning was shared between family members and each had their chance to yarn about their perceptions of health services or the effect on either the child or the family.

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Chapter Six: The Journey of Aftercare for Australia's First Nations Families Whose Child Had Sustained a Burn Injury

6.1 Preface

The journey of aftercare for a child and their family is unique to each family, yet all families experienced similar barriers such as racism, confusion, miscommunication and other barriers mentioned through the voices of the families highlighted in this chapter. Connecting with families in their homes enabled families to yarn freely and without fear about their experiences of their child's burn injury, from the moment it happened, how it happened and what transpired thereafter. In this chapter, I have only focused on the burn aftercare that was received by the child and how the child and the family have been affected by the barriers experienced. Although these barriers are felt in other areas of healthcare, this is the first time that family members have been able to use their voices in the area of ongoing burn aftercare hoping to initiate positive change in this healthcare sector.

6.2 Abstract

Rationale: Access to ongoing multidisciplinary healthcare services for children who have sustained a burn injury is critical for optimal recovery. This paper reports on barriers and facilitators to culturally safe and appropriate burn aftercare for Australia's First Nations children. The voices of First Nations families whose child had sustained a serious burn are central to this paper.

Methods: Eighteen families, which consisted of 59 family members, of children younger than 16 years who had sustained a burn injury were asked to describe their own journey in accessing appropriate burn aftercare. Interviews were conducted in the families' homes using yarning (dialogue) and Dadirri (deep listening) as Indigenous research methods. Data was gathered in South Australia, the Northern Territory,

Queensland and New South Wales, Australia. Using a cyclic process, transcripts and emerging themes were sent back to participants, and a collaborative approach was used to conduct the final analysis.

Results: Lack of culturally safe communication between service providers and family members, in addition to institutionalised racism, were found to be the major barriers to accessing healthcare services. Distance to medical treatment also impacted children's access to aftercare. Involvement of First Nations Health Workers and/or Liaison Officers working with health providers, the child and family members, was found to be an important facilitator in reducing miscommunication and alleviating fear and anxiety in the children and families.

Conclusion: There are significant barriers to access to aftercare following a serious burn including miscommunication, lack of cultural safety, distance to medical treatment and racism. However, these can be largely mitigated when First Nations families have input into the care received and the care needed in order for ongoing burn care to be effective and are supported by First Nations Health/Liaison Officers support.

Key words: First Nations, Children, Barriers, Facilitators, Burns, Aftercare, Health Workers, Liaison Officers

6.3 Introduction

Burn injuries can be devastating not only for the injured child but also for their family and their community. Australia's First Nations children experience burns at a rate at least double that of non-Indigenous children (Australian Institute of Health and Welfare, 2011). To date, there has been limited published research on burns in Australia's First Nations children, and what exists focuses largely on describing the burden using routinely collected data (Duke et al., 2012b; Duke et al., 2011b; Wood et al., 2005b). More recent work led by our team has highlighted the need for changes in policies and practices within the area of burns (Fraser et al., 2018; Fraser et al., 2019).

The accessibility of high-quality aftercare for First Nations children, who constitute a high proportion of burns patients, predominantly those from regional and remote settings, is particularly important, given the complexity of long-term burns care, where access to appropriate treatment is essential to produce good long-term outcomes (Sheridan et al., 2000).

It is well-documented that burns can cause physical discomfort, lifelong scarring, and overwhelming psychological distress. Burn injuries also have an impact on the injured person's family including dislocation from other family members and their communities (Branche et al., 2008). Confusion about and a lack of understanding of healthcare procedures and protocols reinforce anxiety and mistrust of healthcare providers (Aspin et al., 2012). Ensuring that treatment and ongoing care is planned such that families are readily able to access appropriate care is an essential aspect of long-term burns care, but it is unclear how well this occurs in the treatment of burns in First Nations children.

There are documented gaps in access to healthcare by First Nations people, both in primary and tertiary care settings (AIHW, 2011), and there are studies highlighting delays which is suggestive of problems in the interface between primary care and the acute care sectors (Scrimgeour and Scrimgeour, 2007). However, there are no studies on how First Nations children who have sustained a significant burn injury access burn aftercare once they have left the hospital burns unit. This study will focus on this gap by listening to the voices of children and their families through yarning (dialogue) and Dadirri (deep listening) about their experiences and the barriers or facilitators they experienced in accessing appropriate burn aftercare (Walker et al., 2014; Ungunmerr-Baumann, 2002).

6.4 Standpoint methodology

Indigenous methods were applied to this research from inception through to data analysis through the standpoint of a First Nations researcher (Coombes and Ryder, 2019). The use of Indigenous methods prioritises the voices of the families whose child had sustained a burn injury and needed to access burn aftercare (Kovach, 2010).

Indigenous methods employed in this research include yarning and Dadirri, both recognised as techniques to gather stories of families' lived experiences in partnership with the researcher (Wilson, 2001; Smith, 2013). Yarning and Dadirri are forms of communication that are culturally safe and culturally appropriate ways of engaging in conversation (Walker et al., 2014; Ungunmerr-Baumann, 2002; Bessarab and Ng'andu, 2010a). The primary researcher is an Australian First Nations woman whose aim was to decolonise this research project by privileging the voices of the families (Smith, 2013).

6.4.1 The families

Families of 18 children younger than 16 years who had sustained a burn injury were asked to describe their lived experiences of their own journey from the time of injury to the time of recovery including accessing appropriate burn aftercare. Families were recruited purposively from a larger national study examining burn care in Australia's First Nations Children (Ivers et al., 2015). Families were selected to ensure diversity of experience and access to burn aftercare. Data were gathered in South Australia, the Northern Territory, Queensland and New South Wales, Australia, from city, urban, remote and very remote areas. Families were diverse, from those having both parents to one parent homes where the carer was mother, father or a grandparent. Some families had a parent employed while others were unemployed.

6.4.2 Data collection

Families were invited to yarn about their child and family's experiences between 2017 and 2018. All families had either one or both parents that identified as Aboriginal or Torres Strait Islander. Yarns were conducted in the family's home and community using yarning and Dadirri as Indigenous research methods of storytelling. As yarning and Dadirri occurred within families' home and community, there were no time constraints therefore sessions could last hours while sharing a meal, stories and connecting with one another. As experiences from the acute phase could impact on experiences of and access to burn aftercare it was important to understand the whole journey from the initial burn incident, the aftercare, through to the time of yarning together. Once the rapport and connection were established an audio recorder was brought out and, with the permission of the family, recording started. Using a cyclic

process, transcripts and emerging themes were mailed to participants. Phone calls were made to each family to yarn about the findings in their own transcripts, this collaborative approach taken with each family contributed to the final analysis.

6.4.3 Ethics

Ethic approvals for the study were gained from seven Human Research Ethics Committees (HRECs) in Australia. The ethical procedure of this study referred to the relevant guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (Aboriginal and Studies, 2011; Australian Institute of Aboriginal and Torres Strait Islander Studies AIATSIS, 2012).

6.5 Results

In New South Wales we yarned with 5 families who were from urban areas, remote areas and very remote areas. In South Australia we yarned to 2 families that were from urban areas and 1 from a remote area. In Queensland, 2 families were from the city, 2 from an urban area, 2 were from a remote community, 1 family was from a very remote area and 1 family lived in the Torres Strait Islands. Two families from the Northern Territory, which included extended family members, had to relocate from a very remote community in an urban area due to ongoing aftercare for the burn injury. Three families had lost their employment due to their child's burn injury and the time spent away from their homes and other family members. Eighteen children who sustained a burn injury and members of their families participate in the yarning and Dadirri this included mothers, fathers, Aunties, cousins, grandparents and siblings in total 59 family members participated in the yarning.

6.5.1 Communication

Families expressed the need for better communication from health workers. They described feeling confused when they left the burns unit after experiencing a lack of information about the burn care and what was expected once they had left the burns unit. Medical jargon and not being told what would happen next to their child was disconcerting for families, leaving them in fear and feeling angry. Communication

lacking sensitivity and person-centred care was confronting to families trying to calm their child for their aftercare treatment (Table 6.1).

Table 6.1: Communication needs

Lack of information causing confusion	"…I think there is no information or good communication. Because like, you just don't get, like we tried, some things that you don't understand what they're saying, you not getting no information… Like, you know, like with his hand. And then with Madeline,* I'm getting phone calls saying, this appointment from the clinic, to see the doctors, and then all of a sudden they postpone it, and then say, we've got the next one. But that's not with the physio. So they do the physio and the doctor on the same day, and then they're expecting us to go down there to see a physio but then the doctor keeps cancelling, I don't know when the doctor's going to see her, 'cause they keep cancelling. It is sort of a mix up." "I was kept in the dark, and it was just the bits that Brit* was feeding back and that I was reading her notes to get some of the information, but then trying to ask questions, it's like, got to wait until the doctor comes. Doctor comes at 9 o'clock in the morning, I'm not there until 10 o'clock because I just – I can't get up there, by the time I get the other kids organised, so, I've missed everything, and the doctors wouldn't come back and speak to you because they were busy."
Gatekeeping of medical information	No-one would talk to us, no-one would tell us what was going on. It ended up going all night, where they went, "Oh, we don't know what's going on yet. We'll leave it in the morning until the doctor comes in." Finally, the doctor came in the next day... Yeah, and then he goes, "Oh yeah, yeah, we'll get it sorted.

	We'll have to probably send her to [the city] hospital. And we'll get that organised." Anyway, so it probably hit about lunch-time, nothing, heard nothing, like, what's going on with the flights? What's going on with everything? And they just kept going, "Oh, we don't know, we don't know, we don't know." And all this type of stuff, about two o'clock, I went, I can't stand this anymore… This is ridiculous. They're not telling me anything. They're just fobbing me off all the time. So I ended up getting the contact numbers for the Burn Clinic [city hospital] and started contacting them myself. She [nurse from city burns unit] went, "We don't have anything here for her. We don't know what you're talking about." So then she got all the details over the phone and said, "We'll admit her now. We'll get onto the [country hospital] and we'll get it sorted." And within half an hour to an hour, it was sorted. The doctors come in and said, "Oh, we've just been in contact." And I said, "No you didn't. We just contacted them. The burn clinic has just rang you." And they've all kind of went, "Oh"... But the country hospital were atrocious. Absolutely atrocious. I couldn't believe it. They just left you there, you know. Yeah, it was just, like, horrible.
lack of patient/family centred care	"And screaming the way he is, you know, and I said, "Are you sure you're doing it right?" I used to bath him. I said stop it and just wait and let him cool down and they said, "You need to leave, Miss". Yeah, didn't like that much. You know I wish they'd be a bit gentle with how they go because they're not the ones who're burnt. Or feeling all the pain, and yeah like, as parents we've got to watch, and watch our kids go through that pain. But yeah, no one doesn't want to be - no parents want to be put outside the room to let them handle your kids."

	"The doctor came in and said that they were going to take him into the room and pop the blisters and pull the skin off, but I don't think the doctor realised a four-year-old understands that, so then he was absolutely, "No, it's not happening, I'm not doing it," We had to sort of say, "Now Bradie*, that's not exactly what's going to happen; you're going to -" and so we had to explain it in a four-year-old way instead, so I think that they just don't realise what age group they're dealing with. Just being aware of the fact that that child could hear you. He can hear everything you're saying. He's not stupid, and he is four. So he knows, if someone's going to pull his skin off, I can't imagine what he would have thought after being burnt what they were going to do. I mean, the doctors probably could be more understanding of children – I know they're run off their feet, but probably more educated on talking around the child, only because that was fairly traumatic for him when he sort of heard those small things that he could understand and he was just absolutely terrified and it escalated the situation when he was only just calming down."
Medical jargon	"[He] just keep doing his physio and OT (Occupational Therapist) to make his body and his muscles stronger… He has to wear these suits here, his protection burn suits to make his burns like smoother. They [medical staff] talk all these words and that's gone straight over my head, you don't understand what they're saying you don't know what they are doing next." "Oh, yes, sometimes I didn't understand what they were talking about, them words were too big medical words. I didn't have anyone with me and I tried to ask the nurse she kinda explained it to me about more dressings."

Lack of person-centred care	I think the plastic surgeon that came down to have a look at him, he was on his phone talking to the other person [surgeon]; I thought that was a bit impersonal. I think if you're going to do that, come in, check, go out and make the call then come back in. Don't call when you're standing in with the people; thought that was very rude. The surgeon could have come down and have a look and so you weren't reassured, you were thinking, oh, he's just sent his lackey down to have a look at you. Your kid who to you is the most important thing to you in the world you don't know that there's 100 other kids who are doing it, but they're the most important thing to you.

*Not child's real name.

6.5.2 Transport

Overall, transport was an issue that affected every family. Parking at hospitals was costly, sometimes resulting in fines due to appointment times being longer than expected. Distances from hospitals where aftercare was received caused stress on family budgets, schooling and work commitments. Appointments were made by the burns clinic and were not flexible in situations where families had other children to take into consideration (Table 6.2).

Table 6.2: Impact of travel

Burden and impact of travel and cost of parking fees for aftercare appointments	"The appointments taking longer than what you're allocated in your time, and you can't just leave her there and rush out and fix up the parking meter because you've got to park miles away, so, yeah, it was – we ended up with a few parking fines." "I said just take them to the park because otherwise you pay a motza of parking here and I'm like, nah, just go around the

	street and take them to the park and I'll call him when we need to be picked up, so yeah." "And the petrol… Last time we travelled all the way down, and because there's nowhere to stay we just travel all the way back home. Seven hours down and seven hours back for appointments. My two boys have been affected because there's been a lot of times where I've also had to take them out of school. So my little boy has missed out on a fair bit of school because the only time that we would have to come down here for the dressings or for certain appointments that [the country hospital] don't provide, I've had to take him because I can't leave him there. So he's missed out on a fair bit of school, Kath* also. You know, she's in high school now and I've got to drive down here, have appointments, then drive back. That's a minimum of three days if you want to push it, of high school days every month or two. Yeah, it's really affecting her school attendance as well as my little boy's school attendance, which isn't good."
Intransigent appointment times	"And my disabled son, goes to school on his own schedule, if he wakes up at 8.30, 9 o'clock, then I can get him off to school, but I have to drop him off at school and I explain that to them and they still made her appointments for first thing in the morning when I ask them for later appointments, and it's like, really? So, we were late, so then they'd make us wait, so we could be there anywhere from four hours, I think, was our longest appointment."

*Not child's real name.

6.5.3 Child, parent/carer, family support

One of the biggest challenge's families highlighted was the lack of local support or services for aftercare treatment. Services, nurses or allied health workers trained in the area of burns aftercare was especially important. Written, culturally appropriate information that was easily understood about the aftercare needed with contact numbers was a request each family shared. The need for contact numbers for local support agencies to assist with emotional support for family, child or single parents was also commonly voiced (Table 6.3).

Table 6.3: Family support

Lack of local service providers disrupts family routines	"It would have been easier if maybe somebody could have organised someone to come here to change his bandages, instead of me taking all the kids down to the hospital all the time. They do it after you have a baby, they come out and check on you in your house, so I'm not sure why something wasn't organised for them to come and change the bandages here, instead of making appointments every second day to come down [to the city hospital] with three or four other kids in tow. So yeah, it was pretty annoying. There are no local people to do the dressing here." "We're all very tired. And my second eldest has … and possible autism. So, it's hard on him as well, going to other people's houses. The kids have had to miss a bit of school. I miss things that they do at school, as well as taking them to school. So, Maison*, the second oldest, missed out on the pet parade and I organised for a friend to take him, Ellie the dog, and she (Ellie) didn't feel like it. So, Maison* had no pet for the pet parade, because I was in Sydney with Luca*. They get split up sometimes having to stay at different people's places for days."

Needed support for single parent families	"Mine would be the lack of support for single parents. When you have no family where you live and they want to fly you out, but you can't get a flight out because you have another child and they won't take extra children on the flight and then you have to drive with a kid that has an injury of a burn, you've got to drive nine hours to get there by a certain time and also the hospital that don't cater for single parents to have to actually have the kids stay there because there might not be another option."
The need for information for ongoing emotional support	"An information pack would be good to step you through all the emotions you go through and probably even the emotions that you're going to feel after it happens and who to go to for help. You run through it constantly for days. You can't sleep because you just – it's always running in your head – up until you know that they're going to be ok. Once I knew that it was all okay and that we'd finished the process, then it was – it sort of subsided, it went away, but in those times, you just constantly were thinking what could you have done, and you'd have dreams about what would have happened if you didn't have the ice, the water, you went through all those emotions of what would have happened if we didn't have that."

*Not the child's real name.

6.5.4 Family separation

Strong emotions were expressed when yarning about family disconnection. Families were separated for long periods of time and those with large families had to split up their other family members causing detachment. Being separated from their other children caused additional stress to the parent/carer. The child who had needed to travel large distances for aftercare became distressed at being separated from other siblings (Table 6.4).

Table 6.4: Family separation

Fractured family causing detachment from self, people, Country	"It is when you've got 13 children it's very hard. And then like leaving them to go to [city burn clinic], when you think of taking them and all the way down there, it's just not fair. It's a long way away. If something happens you can't say, "I'll be there now," or, you know? I worried being away from them." "Yeah it has affected us a lot because it's like split us all up, you know, with the – with the other two being away separate from us. I've only got these two and yeah, and it's like he doesn't really understand yet like what's happened and that. He – like he's yeah, doesn't realise yet of the outcome of the burn and that and he doesn't talk about it, you know, and when you ask him he says, "No it's all right I don't worry about it." Yeah, but later on down the track I think he will when he gets a bigger boy, yeah, when he starts growing into a teenager side." "I felt sad when I was down there because you don't know, you know no-one. Too far away from families. I was lost down there. My boy was a bit sad too. Everyone here is related or ours. Because everyone's cousins and all around here, and over the hill. I've got sisters up town there, and brother. This our community we help each other."

6.5.5 Racism

The families told of their experiences of racism they had endured while engaging in Australia's healthcare systems. Families told of feeling judged and disempowered and described the colonialism they experienced as a family while their child was being treated for the burn injury (Table 6.5).

Table 6.5: Racism

Assumptions	"Well another thing, I mean we were in the room by ourselves and the nurse, … walks in and says, "You're going to be right, your people's come into the room." And I went, "Huh?" "Oh, no you'll be right, all your people are coming to the room." It was a family, Indigenous family that got burnt out of their home and all that smoke inhalation. That was the whole family, at the same time that happens to you. Yeah. My people were coming. I didn't know them from a bar of soap. They're not our bloody people. Yeah. So 'cause I'm Indigenous and that's how people put them all in the one room."
Judgementalism	"If my kids come and did this it would be a totally different outcome and we know it, we know it. We see it every day the difference, our kids are judged to the other kids. They think our kids are wild, they just playing"
Interpersonal racism	"One night there was a light switch that wasn't working, that was broken, and I went to turn that light switch off but I couldn't because it was zapping green behind the thing so I left it because I didn't get zapped and then the nurse came in that night and I said to the nurse, "Excuse me but this light is broken you know we're not going to lay down with the light on all night, I have to get up 6:30 in the morning and get Matty* ready." And she turned around and she said, "Well love you'll just have to get a sheet or a towel and just put it over your eyes." And I said, "Oh yeah, okay then thank you." Next day this nurse walks in and she was talking real smart to me. She goes, "Oh the light's working. Yeah you might have brains not

	to go and touch it, you might have got zapped you know." They think we are dumb because we are Aboriginal."
Racism in the form of punishment	"Mark* didn't want them doing anything to him because he thought that you know, they might hurt him and he was using it in a like swearing way towards them, and they just kind of thought no, we can't deal with him. You know they all was like that, "No, we can't deal with this kid," you know, and like a couple times he was swearing really loud and they took the TV away from him to try and learn him. Took his food away and put it out on the table outside. Took his lunch, got his lunch took it outside and put it on the table. And took the cable from the TV, took it away. And I said "there was white kids in there doing that." And they was, really noisy with that. White children was in there and they was doing the same and no, TV didn't go off nothing, they had lunch, they [nurses] was like yeah, and rolled eyes at me."
Lack of cultural safety	"And it's when you're a good mother and you feel like discriminated on that… Seeing people that look like junkies in there, and they get treated worse. Indigenous, because they look like junkies they get treated bad too. Another Indigenous family waiting, they were treating them really bad just because of the kids playing." "They just set us the rules for us, oh yeah some are racist, because like some of them, they're – oh they're really, just not really nice. It makes you not want to come back."
Disrespect leading to disempowerment	But they need to better respect the parents you know of the children that's going through this because we've been through enough you know. We were stressed right out from you know,

	your kid nearly dying to helping your kid through the process of getting better and healing. You know, they just need to start respecting parents and you know, treat them kind. You know, and not being sour to people, smiling at them and asking them are you all right, you know, do you want help with that, you know, or something like that. They make us feel like we are dumb and can't do nothing to help our child." "They wanted to take Jack* to [the city hospital] and I said, "I can't drive." So they said, "Well, he really needs to go to [the city hospital] but we'll organise an ambulance to [our country hospital] for a dressing." The nurse here said to me, "They don't worry about the people in the scrub" [and] the person from [the city hospital] rang and said to me, "Well, move to the city and you'll get treated better."
Lack of professionalism contributing to ongoing systemic racism	When we walk in the room you know by the look on the face that they [nurses] think we are all the same, no good"… we try to change but we're still the same to everyone … even the nurse they can just look at us and they [nurses] think he's still the same…You can never prove yourself." "They just set us the rules for us… some are racist, because like some of them, they're look at us funny, oh they're really just not really nice. It makes you not want to come back."

*Not the child's real name.

6.5.6 Healing in rural and remote communities

Staying in remote and rural communities with family and support systems was also identified as important for the ongoing health and wellbeing of the child and family. Families expressed the need for practical information on burn aftercare, as well as the

aftercare being accessible to them in community clinics to lessen the stress and burden of travel and family dislocation (Table 6.6).

Table 6.6: Community support systems

Importance of family, home and Country in aftercare	"We did get help in the community. We did get a lot of support. Community helped a lot with my other kids, like family. Family helped rub cream on him all the time, to give me a break. There was always someone to take my daughter to her appointments." "Yeah, there's three – our three sisters and two brothers and all our kids from our siblings, all our nieces and nephews, they all call us mums and dads. There's three mums and two dads plus grandfathers and other mums. But we're a tight little group, but all Aboriginal families have all got that connection with kids. It would be good if we could get help from home hospital and stay together. No matter that's your – my big sister, that's your mum too, and so on and so on. You can have 10 mums; be the richest kid in the world."
Information needed for the parent to help with home aftercare.	"I think just someone that I can actually talk to and just say hey, look, is this normal, is this not? would be good. And just, even if it's phone contact once a month or something like that, just to touch base and say how's things going, then, yeah. But it was – I've been through one child having open heart surgery but this was completely different. It's, kind of, this threw me because I didn't have any information I didn't know what to do when we got home."

Training needed for remote and rural health workers in burn aftercare	"Because even [the country hospital] when they sent us over to do it, the dressing, the lady was lovely, you know, can't be helped, but Layla* wasn't happy with the dressing. She was scared it was going to get infected. You know, like I wish we had more people trained for the country. Country nurses need teaching with burn dressings."

*Not the child's real name.

6.5.7 Trauma

Trauma was evident when families in the study spoke about their child's burn injury and the family's journey through the healing processes. Although the child was treated for the burn injury in the burns unit, during the long process of aftercare there was no recognition or treatment for the psychological effects resulting from the injury for the child, or the one who caused the injury, or the family. A family experienced trauma through the removal of a sibling of the injured child to welfare other families were traumatised by fear of their child being removed (Table 6.7).

Table 6.7: Trauma

Trauma cumulative and/or unrecognised	"See and then we've got to move around and do everything now, we've got to transfer and leave our home our family, he has to be close to [city hospital]. Yeah, I don't want our family broken. It would be good to have just one person to help our family stay together. My kids are all over the place." "Couldn't sleep over it all. Just seeing them on fire like a matchstick, still after a year can't sleep 'cause it's very stressful. I cried a lot by myself."

Effects of the trauma on other family members	"My big sister Immy*, she said, "No, this boy's really broken, Natasha*." I said, "Yeah, poor darling." His mother had to take him into hospital and the clinic there where they stay in the community and get him some sort of help, try and help him with a bit of sleeping pills, or something, put him to sleep, because he used to get up and just cry for Andrew* and constantly trying to ring up and find out how Andrew* was and kept saying sorry over and over on the phone, and that was sad for me." "He [Andrew's* brother] sometimes he gets angry and he goes, "Yous are blaming me, yous are blaming me for Andrew*." Yeah but he just hides his things and he doesn't talk about it or let it out… Yeah and he was missing me as well when I was gone. Like he wasn't understanding properly why mum and Andrew* are gone for so long. Yeah and we tried telling him but we have to go because Andrew* needs you know, proper care and proper treatment… Yeah, and then he [brother] thought that we gave him away that's what he's, that's the other thing he's thinking and we tell him, "We never gave you away. We're just waiting till we get this house and then you're coming back to us."
Trauma of child removal by child services and the unnecessary reporting to child services	"There seems to be a lot of DoCS (Department of Community Services) calling on our kids. it's like it was our fault and like they made us – made me, my partner he was there, we walked in the room with the DoCS and I just jumped up and I said, "What, I don't care, you know, I'm sick of this, I've never done [swearing] nothing wrong myself." Well, I just slammed the door and my partner said, "You shouldn't have done that," you know he was scared"

	"They didn't (treat us well) Up – while we were down there the DoCS worker come because nurses, apparently the DoCs lady told me that they Chinese whisper in the hospitals. So little Chinese whispers caused DoCS onto us. So that was sort of very upsetting for me at the time as well, thinking what the hell did we do? It was a 19 year old that done it. That had all got fixed up, as we came home we – the police chucked it out the window as the DoCS people said, and the DoCS knew, like it was an accident…But yeah, that – you didn't feel really safe at all. "The DoCS people… they were investigating Sam's* burn…They [hospital] must have had a report or something that he's burned, but they were investigating how it happened. I think they've closed the case now. They rang up and said they were going to close it, but I haven't heard anything from them at all." "Dad was left home with our other kids and Derrick* felt bad and he ran away and hid in the big bin and slept there, in the morning the big truck come to empty the bin and thank God he heard him screaming and pulled him out of the bin. Dad thought Derrick*was at his grandmothers but the police called dad and told him to come to the police station and they said he had to sign Derrick* over to care otherwise they would also take our baby too so dad had no choice but to sign him over to care. I was in the hospital 1000s miles away thinking my boy is going to die and dad calling me telling me about Derrick* being taken away, I was broken, he is still in care but we will get him back when we get a place to live. It has affected us a lot because it has split us all up."

* Not the child's real name.

6.5.8 First Nations Health Workers/ Liaison Officers

Most families expressed a lack of understanding about their child's aftercare as well as a lack of understanding of the medical jargon used. Involvement of First Nations Health Workers and/or Liaison Officers working with health providers, the child and family members were voiced as important to improving communication, accessing ongoing healthcare and supporting the family (Table 6.8).

Table 6.8: Importance of First Nations health workers

Person-centred care and support	"We had to move from our community and no family is here but yeah, she [Aboriginal health worker] helped me with like food vouchers, and sit down and have a cup of coffee and a yarn at the hospital house they sent us to so Sonny* could have dressings" "I ended up giving her a gift after she [Aboriginal Health Worker] done what she did, she supported me a lot and kept an eye on him and, so, I done her a nice painting she took home. She loved it."
Facilitators to ongoing access to aftercare	"The [Aboriginal] health workers, they brought me up a few times for our appointments, I think a couple of times." "We had to move into the hospital house and share with other Aboriginal families for a few months then they got us this house by ourselves. He needs to still see the physio. No, I don't have a car, we either catch the bus to the hospital or the health girls [Aboriginal health workers] came and picked us up. "Abby* liked her [Aboriginal health worker] she was happy when she saw her the next time we went for dressing 'cause we trusted her"

Communication	"It was so good having her [Aboriginal health worker] there when they were talking them big words she would tell us what they meant"

*Not the child's real name.

When families were asked to prioritise the importance of the themes emerging from this study, the families identified transport and dislocation from family and community, racism and lack of culturally safe communication as critical elements affecting burn aftercare. A significant positive facilitator to burn aftercare, mentioned by each family, was the importance of First Nations health worker who they described as having a role in maintaining the wellbeing of child, family and culture.

6.6 Discussion

6.6.1 Main findings

This is the first study that privileges the voices of Australia's First Nations families on access to burn aftercare for children. Highlighted in this section are some of the significant systemic barriers to burn aftercare, which include but are not limited to, the lack of culturally appropriate communication, racism and distance from burn aftercare and family separation. The families that shared their experiences highlighted barriers which led to multiple and unnecessarily lengthy hospital visits for treatment and aftercare of their child's burn injury.

6.6.2 Racism

In line with the work of Durey, Thompson and Wood, who discussed the need to address institutional racism and misunderstandings in communication, our results similarly show that the issues are the same for burn aftercare and particularly emphasise the need for cultural change to address the systemic racism experienced by First Nations children and their families (Durey et al., 2012).

Racism is a word that continually comes to the forefront not only in Australia but globally and needs to be addressed if equity and equality are to be attained in

healthcare systems. Western biomedical frameworks which reinforce colonial power structures, has been the platform on which health policies have been developed, and continues to marginalise Australia's First Nations concept of health and wellbeing in our healthcare systems (Durey and Thompson, 2012). Institutionalised racism does not encourage ethical, respectful or culturally safe healthcare for Australia's First Nations people; Durey and Thompson propose that *"In order to ensure culturally safe health service environments, both institutional and personal commitment is required'* (Durey and Thompson, 2012).

Families spoke of a breakdown in communication within and from the multidisciplinary team which led to a lack of coordinated care between the tertiary and primary healthcare systems. Because there is no coordinated care between the systems, families missed appointments which further reinforced the stereotypical assumptions that First Nations families don't attend follow-up appointments, when in fact they did not attend due to the breakdown in communication, false assumptions and racism.

Interpersonal and systemic racism by healthcare providers was experienced by the study families, discouraging them from attending future appointments. In addition, some children feared having to return for further treatment because of the culturally unsafe treatment they had previously received from the healthcare providers. The families reported that previous treatment by healthcare workers left their child and family members traumatised.

6.6.3 Transport and family separation

A further barrier to children and families attending burn aftercare is the significant distance between burn aftercare facilities and family homes and the lack of transport services forcing dislocation and separation of families. This was demonstrated by Fraser et al. in a study which found that transport and distance from home and community were not taken into consideration in healthcare practices (Fraser et al., 2018). For instance, when one parent was caring for the child with the burn injury at the burn clinic, the other parent was elsewhere caring for the remaining children.

Dislocation led to the family's other children being at risk of removal by child services, this was highlighted by multiple families who participated in the yarning.

Families also spoke of a lack of planned processes for further management with the multidisciplinary team to ensure the best outcomes following their child's discharge from the burn unit.

Some service providers encouraged relocation to the city from remote communities leading to displacement of the families. Families were told that their child would not receive the level of care needed, and that they should move from their community and home to live in the city.

Families shared how they felt these racist and colonialist statements did not take into consideration the importance of their connection to Country. To First Nations people, Country means connection, it is a spiritual belonging, and community and family are paramount to their psychosocial and cultural wellbeing. Families spoke about community being a place where many mothers and aunties help raise a child, and that comments like "you should move" amplify the issues of distance and led to experiences of hopelessness for First Nations families whose child required ongoing aftercare (Dudgeon et al., 2010b).

6.6.4 First Nations workers

Communication was expressed by the families as one of the leading barriers to accessing burn aftercare in Australia. An example in this study was use of medical jargon *'... I didn't understand what they were talking about, them words were too big medical words..'* to answer families' questions which effectively left their questions unanswered.

However, the presence of First Nations Health Workers as mediators and interpreters of the medical jargon enabled the child and family to understand in lay terms what had happened and what would happen in the future regarding their child's burn aftercare (DiGiacomo et al., 2013).

Parents acknowledged that without First Nations health worker involvement, there was no connection to culture for their child or family in the burn clinics. Furthermore, families stated that engagement of a First Nations Health Worker enabled trust between the service providers and child and/or family. Studies from Australia have shown that the involvement of First Nations Health Workers was crucial in creating culturally safe and appropriate healthcare systems for aftercare and cultivated trusting relationships between multidisciplinary team, the child and families (Coombes et al., 2018a).

6.7 Strengths and limitations

The primary strength of this qualitative study is that it uses Indigenous methodologies and prioritises the voices of First Nations families whose child had sustained a significant burn injury and needed access to burn aftercare (Coombes and Ryder, 2019).

Another significant strength of this paper is in the design where following transcription, the transcripts were sent to families for confirmation of accuracy and feedback, reflecting an alignment of the families' views and ensuring their voices represented the researcher's interpretation of the journey of First Nations families whose child had experienced a burn injury.

A limitation of this study is that we were only able to recruit First Nations families whose child had experienced a serious burn injury from five hospitals in Australia where paediatric burn services were offered. First Nations children who were treated in outpatient centres not included here may have had different experiences that were not captured in this study.

6.8 Recommendations

There is a lack of cultural competency and safety in healthcare for Australia's First Nations people, creating barriers in access to health services, including burn aftercare. The lack of culturally competent communication causes fear, distrust and anxiety to the child and to family members. Aftercare cannot be separated from the initial care

received, as it influences not only short-term but also long-term recovery for the child and the family.

A planned process enacted in a culturally appropriate and safe way would take into consideration the needs of all involved in the burn aftercare, including the multidisciplinary team, the First Nations Health Workers, the family and the child. Ensuring a clear pathway for the child's aftercare needs, which is understood by the family, can lead to an easy transition to the multidisciplinary team from the burn unit to optimal healing for the child.

First Nations Health Workers had a positive influence on the impact for ongoing health and wellbeing as well as supporting the aftercare processes for healing. However, the role of First Nations Health Workers in supporting families and having an integral role in burn aftercare has not been recognised in Australia's health systems to date (Cresp et al., 2016); (DiGiacomo et al., 2013). First Nations children who have experienced a serious burn and need a multidisciplinary team for ongoing aftercare to achieve a healthy, happy and productive life would benefit from the continued support and involvement of First Nations Health Workers.

The United Nations Declaration on the Rights of Indigenous Peoples clearly states that First Nations people globally have the right to best practice healthcare no matter where their choice of residence is (Assembly, 2007). Australia's First Nations children also have the right to appropriate and beneficial aftercare for their burn injury to have the best outcomes for healing regardless of proximity to healthcare services.

> *"Somewhere closer to [for bandages or physio] instead of travelling all that way. So you're really far away from your family... I'd love it if they had it in [Country places] or something like that. Not saying that my kids are going to get burned again, but it's just for all families."* (Mother from remote community)

Collaborative and supported burn aftercare education and training for parents from experienced health workers to assist with home aftercare and added access to a burns

unit for any queries parents may have will alleviate the need for constant long-distance travel, and therefore families can remain together and reduce dislocation.

The continued culturally unsafe practices experienced by the children and their families further reinforces racism in Australia. Health services in Australia need to incorporate culturally responsive healthcare as part of their routine burn aftercare. Training is necessary to foster good communication, stop racism and stereotyping, which in turn will encourage families to engage in aftercare appointments (Haas, 2016). Training health workers in culturally responsive care ensures they are responsive to First Nations children and families' needs in a vulnerable space.

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Chapter Seven: "They are worth their weight in gold": Families and clinicians' perspectives on the role of First Nations Health Workers in paediatric burn care in Australia

7.1 Preface

In the previous chapter I highlighted barriers as well as briefly touching on facilitators in accessing burn aftercare through the voices of family members. This chapter brings together two subsets of data, one from myself (sub-study 1)and one from another PhD student and colleague (sub-study 2) who is also a research assistant on the larger project investigating burn injury in Aboriginal and Torres Strait Islander children, "The Coolamon Study" (Ivers et al., 2015a). The included data used in this chapter for sub-study 1 was utilised from the family's time of yarning and Dadirri about their child's healing process, the barriers and facilitators to burn aftercare and their family's journey through out the healing process which is mentioned in more detail in chapter three and throughout the thesis. However only data that included descriptions of FNHWs' involvement in multidisciplinary burn care from the perspectives of the workers themselves and of multidisciplinary burns team was used from sub study 2. This chapter focusses on the actual and/or perceived role of First Nations Health Workers in burn care from the perspective of family members, First Nations Health Workers and the multidisciplinary team members by bringing the two data sets together as one. Importantly, it emphasises the importance of including First Nations Health Workers in the ongoing and complex care that is part of burn aftercare.

7.2 Abstract

Burns affect Australia's First Nations children more than other Australian children. First Nations children experience longer lengths of stay in tertiary burns units and face barriers in accessing burn aftercare treatment. Data sets from two studies were

combined whereby 19 families, 11 First Nations health worker (FNHW) and 56 multidisciplinary burn team members from across Australia described the actual or perceived role of FNHW in multidisciplinary burn care. Data highlighted similarities between the actual role of FNHW as described by families and as described by FNHW such as enabling cultural safety and advocacy. In contrast, a disconnect between the actual experience of First Nations families and health workers and that as perceived by multidisciplinary burn team members was evident. More work is needed to understand the impact of this disconnect and how to address it.

Key words/phrases: FNHWs, burn aftercare, children, Australia

7.3 Background

First Nations Health Workers are employed in tertiary health settings around Australia to improve cultural safety and enhance interactions between First Nations people and the Australian healthcare system (Giblin, 1989). Studies demonstrate improved health outcomes and communication when FNHWs are involved in care in tertiary healthcare settings (Taylor et al., 2009). Other studies also show that involvement of FNHWs in care has led to improved access to aftercare for children with chronic conditions (Coombes et al., 2018b; Dahhan et al., 2012b).

Burns can be a devastating injury causing long term physical and emotional trauma (Sheridan et al., 2000). Australia's First Nations children are admitted to hospitals as a result of a burn injury twice as often as other Australian children and have longer lengths of stay (Möller et al., 2017b). Serious burn injuries need specialised acute tertiary care and often require multidisciplinary aftercare for extended periods of time (Sheridan et al., 2000). Given the reported benefits of their involvement in other care contexts (Chang et al., 2007), it is clear that FNHWs are important facilitators to the continuity of burn aftercare once a First Nations child has left a tertiary healthcare setting.

Burn care is informed by Western biomedical concepts of health (Fraser et al., 2019), despite First Nations family needs for best quality healthcare. Quality healthcare is such that it incorporates First Nations concepts of health and healing and delivery of

care by FNHWs. However, how FNHWs work in the healthcare system at the interface of Western biomedical care and First Nations concepts of health and healing in relation to childhood burns is unclear.

To our knowledge, this is the first study to describe the role and function of FNHWs in multidisciplinary burn care for Australia's First Nations children. The desired, actual and perceived role of FNHWs is described by families and the FNHW themselves, along with data from the perspectives of multidisciplinary burn team members.

7.3.1 The Coolamon Study

The larger study called the Coolamon Study looks at the care received, cost related to the burn care, describe the relationship between care and functional outcome, and identify barriers and facilitators to receipt of appropriate care. The study has been developed to ensured concepts, wording and culturally appropriate methods of management are appropriate, providing evidence of feasibility and ensuring appropriateness of methods for this study. The study is working in partnership with clinicians, policy makers, Aboriginal Health Services and the community to develop a 'blueprint' for reforming services which will ensure that Aboriginal and Torres Strait Islander children receive appropriate and cost-effective care. Participants were interviewed at baseline and 3, 6, 12 and 24 months afterward at each site in Australia. Clinical information on burns, and care received, has been extracted from the medical records. This is the first cohort study of its kind and is still in the last phase of clinical data collection. Australia's First Nations children under the age of 16 years who had sustained a burn injury and present to a tertiary paediatric burn unit were recruited from New South Wales, Queensland, South Australia and Northern Territory. Data collected from this study included sociodemographic information, out of pocket costs, functional outcome and measures of pain, itch and scarring. It also explored what the barriers and facilitators of burn after care were for the family. Health-related quality of life was measured using the PedsQL, and impact of injury using the family impact scale. Clinical data and treatment will also be recorded. *(Ivers et al., 2015a) Within this larger study two sub-studies were conducted by JC and SF undertaking their PhDs.*

7.4 Methodology

The Coolamon Study (Ivers et al) comprises four sub-studies. This paper reports on data from two sub-studies led by authors JC and SF. To better understand the role and contribution to care by FNHWs in multidisciplinary burn care for First Nations children, data from the two sub-studies were combined. Data included incorporates the perspective of families on the perceived and desired contribution to burn aftercare by FNHWs from sub-study one. Data from stub-study two includes the descriptions of FNHWs' involvement in multidisciplinary burn care from the perspectives of the workers themselves and of multidisciplinary burns team. The combining of the two data sets is essential in facilitating a comprehensive understanding of the role of FNHWs from multiple perspectives and lived experiences regarding burn care for First Nations children and their families.

7.4.1 Analysis Approach

First sub-study

The first set of data was collected by the first author JC, an Australian First Nations researcher, using Indigenous research methodologies. The first author, JC's worldview as a Murri woman impacted her standpoint in this sub-study (Smith, 2013; Coombes and Ryder, 2019). JC sought to understand the barriers and/or facilitators in accessing burn aftercare using Indigenous methods of yarning (Geia et al., 2013) and Dadirri (Ungunmerr-Baumann, 1988). A total of 59 individuals from 18 different families were asked to share their burn care journeys. Families resided in communities across Australia and the Torres Strait Islands. These stories were audio recorded and transcribed verbatim. Families received a copy of their transcript and a follow up phone call was made to ensure the family's stories was accurately reflected. Data were analysed using a cyclical process which gave ownership of the story to the storyteller and empowered the voice of each family (Coombes and Ryder, 2019).

7.4.2 Second sub-study

Interface research methodology (Durie 2004) incorporating both Indigenous and Western biomedical knowledges guided the second sub-study for author SF, a non-

Indigenous researcher. Sub-study two sought to explore how burns care is delivered, with a focus on the care of First Nations children and families. It also investigated factors informing burn care and explored how clinicians in burn teams use guidance documents and if such documents are appropriate for care of First Nations children. In the second sub-study, author SF interviewed 76 healthcare professionals from six different multidisciplinary burn teams across five jurisdictions in Australia. Of the 76 participants interviewed, 11 were employed in First Nations specific health worker roles. These included one Aboriginal health practitioner and 10 Aboriginal or Indigenous liaison officers. Interviews were also audio recorded, transcribed verbatim and participants confirmed the transcripts were accurate and true. Data that discussed the specific role, either perceived or actual, of FNHWs have been included here.

Individually authors JC and SF analysed their own data and then came together to consolidate their findings and discussed over all themes with the third author TM who has expertise in Indigenous methods and from there reached consensus on the key findings and research themes. Both studies specifically explored the role of FNHWs in delivery of burn care, both acute and in aftercare. Combining the data of First Nations author JC's study informed by Indigenous methodology (Kovach, 2010) with the data from non-Indigenous researcher SF who engaged interface research methodology (Durie 2004) was deliberate and purposeful. This gives a breadth of context (understanding the entire patient journey) and depth of understanding (how the role participates in the team and how the roles meets the needs of the families across the journey). The combination of data provides an opportunity to further explore the role of FNHWs in burn care for First Nations children. Furthermore, the coming together by the two researchers and their respective methodologies, provides an opportunity to demonstrate how research at the interface might deliver outcomes that marry Indigenous ways of doing and Western biomedical care. JC, SF and TM met to discuss the data and existing themes, then grouped data (as per result below) and then synthesised information into specifically

7.5 Results

Results from both sub-studies highlighted the role of FNHWs in delivery of burn care, from a patient and family perspective (study 1) and from a clinician perspective (study 2). The data have been arranged into three sections, the FNHWs' perspectives of care, the multidisciplinary burns team perspectives of the role, and the First Nations families' perspectives of the FNHWs' role. Quotes have been used throughout to illustrate the themes that were synthesised from the data and pseudonyms used to protect identities where necessary.

7.5.1 First Nations children's and families' perspectives

Remote participants needing multidisciplinary teams for ongoing burn aftercare described the importance of the FNHWs in supporting children and families accessing burn aftercare. Families recounted how FNHWs provided access to essential tangible support and a culturally safe environment. Families also identified challenges related to the role of FNHWs and their availability to be involved in their child's care (Table 7.1). Several sub-themes were identified within these aspects of care.

Table 7.1: First Nations children's and families' perspectives

Tangible support	**Cultural Support**	**Challenges and fears**
Communication/ interpreters Accommodation Food Transport Help with aftercare appointments	Cultural and spiritual care Connection to people and place Cultural safety/ Advocacy Trust	Lack of cultural understanding from non-Indigenous health professionals Not understanding the medical jargon when FNHW was not available Not having a FNHW at the hospital Overworked and not available Fear of child removal

Tangible support: FNHWs were able to assist families with tangible support in transporting the child and family to appointments, with short- and long-term accommodation, food and taxi vouchers and filling in forms for the patient assistance transport scheme.

> *"He needs to still see the physio. No, I don't have a car, we either catch the bus to the hospital or the health girls [FNHW] came and picked us up."*

> *"She [FNHW] took off my PATS [Patient Assistance Transport Scheme] form and faxed it off to me".*

> *"The [First Nations] health workers, they brought me up a few times for our appointments, I think a couple of times."*

> *"We didn't have anywhere to stay but she helped us with a place while he had his dressing done… every few days we'd go back to the hospital with taxi vouchers she gave us"*

Cultural support*:* Families voiced how dislocation from home and community was understood and valued by the FNHW. Due to FNHWs' advocacy between the multidisciplinary team, health services and the family, a connection was created between First Nations families and FNHWs.

> *"I ended up giving her a gift after she [FNHW] done what she did, she supported me a lot and kept an eye on him and, so, I done her a nice painting she took home. She loved it.*

> *"Linda* liked her [FNHW] she was happy when she saw her the next time we went for dressing 'cause we trusted her"*

> *"She [FNHW] understood where we come from and how different it is down here they [multidisciplinary team] don't understand"*

> *"We had to move from our community and no family is here but yeah, she [FNHW] helped me with like food vouchers, and sit down and have a cup of*

coffee and a yarn at the hospital house they sent us to so Maison could have dressings"*

Challenges and fears*:* Data showed that some children and families were frustrated that FNHWs were not available when they needed them. This was often because they were either busy with other patients or there wasn't a FNHW employed at the service. When FNHWs were available to provide support, family challenges and fears were alleviated. Although some families did not receive support from a FNHW it was express that they would have liked to have the support.

"No, but I wish I did see one [FNHW] then she could have been with me when mum couldn't." (child)

"I don't think I seen anyone else – any Aboriginal worker they said they had one but was sick." (mother)

"Yes I did see an Aboriginal worker… Once for about 20 minutes. She was going to come back but she didn't come back. Obviously it was flat out" (mother)

"It was so good having her [FNHW] there when they were talking them big words she would tell us what they meant." (mother)

"The Aboriginal [liaison] worker helped get my family together down here… going to be here for months in Ronald Macdonald house… we were all living in separate places… so hard on Damien's father." (mother)*

7.5.2 FNHWs perspectives on their contribution to burn care

FNHWs were essential to the cultural safety of the child and the family, often acting as advocates between family and medical staff. There was a clear message from FNHWs that the need for cultural awareness training for non-Indigenous health workers was imperative in providing cultural safety and support for First Nations families. Data showed the provision of two main areas of support by FNHWs to include tangible and

cultural support. Data also highlighted the importance of working together and the challenges associated with the role (Table 7.2).

Table 7.2: First Nations health workers' perspectives on their contribution to and challenges with burn care

Tangible support	**Cultural support**	**Two worlds working together**	**Challenges at work**
Connection to people and place Accommodation Food Transport	Cultural and spiritual care Communication/ interpreters Cultural safety/ advocacy Training/education	Called upon if problems with families Communication Advocacy Training/education	Not able to be involved from the start Lack of communication Working above and beyond Overworked

Tangible support: Transport for the child and family was difficult from remote communities, and FNHWs would organise the crucial transport for the child to receive ongoing burn aftercare, alleviating some of the stress family were often face with.

> *"But if it's an outpatient we'll sort that out as well and help the family. We used to help them with taxi vouchers but now taxi voucher are getting really, really scarce and it's really frustrated because we get families who missed their flight, and I'm not going to tell a family catch a bus and go from here to there, it's not fair. So we have to fight for taxi vouchers." (Aboriginal Liaison Officer)*

> *"So at the moment my role is, I give health education to patients, I help them understand why they're in the hospital, I help with any issues around social stuff within reason because the ILOs [Indigenous Liaison Officers] are employed for that role but because sometimes they're short staffed… our roles overlap a little bit and that's the whole role of the AHP [Aboriginal Health Practitioner] is the primary health care, is the holistic approach to health so sorting out everything. I also advocate for patients who need spiritual healing or cleansing, unfortunately (this hospital) don't provide that service or support that service so I try my best to get that patient to*

communicate and navigate through the system with having that need addressed, the spiritual need addressed as well the Western medical need." (Aboriginal Health Practitioner)

"…Aboriginal Liaison Officers who are based on the ground floor and they do outpatients but it's more escorting them to appointments, booking them back home and stuff… those guys [patient/family] if it was a burns clinic outpatient appointment they probably wouldn't receive really any support without this." (Aboriginal Liaison Officer)

Cultural support*:* Supporting First Nations families through cultural connection helped with effective communication between multidisciplinary team and families. This was expressed by FNHWs as an important and essential component of their role.

"Cultural advice you know or cultural safety on the clients say if they, we do a research and find out the language, where they're from and what traditions they have in their community and if they, you know some of the patients don't want to be seen by females so we have to let them know. Just making sure that staff are safe too and the patient's safe." (Aboriginal Health Practitioner)

"… where the patient really fully understands or the patient's parent or guardian fully understands what's going on with a particular patient and will make an informed decision around that patient's care. So there's a lot of cultural barriers around that and you know like for me I think our cultural awareness training really lets staff down because it only addresses the first part of the cultural continuum of going towards patient cultural safe, delivering a culturally safe service..." (Aboriginal Health Practitioner)

"English is probably their third language it's still funny though, I don't know how to explain it but we can still connect." (Aboriginal Liaison Officer)

Two worlds working together*:* FNHWs functioned as advocates for the child and family and as mediators when working with the multidisciplinary burns team. There

was recognition that FNHWs and the multidisciplinary team need to work together for the benefit of the child and family in order to contribute to better healing outcomes.

> *"I think if you understand what the organisation expects and you understand the upbringing that you were raised in and you balance them out you realise how you can actually go about it and bring both of the worlds together and that means the outcome for the families is, you're going to achieve something." (Aboriginal Liaison Officer)*

> *" I've just always been asked can you come and talk to them, or they're not going to turn up for their physio appointments or they're not getting out of bed for me can you go, them kind of things but I've never really been asked culture-wise stuff whether it's because they've been around long enough they've got that knowledge and experience, but yeah I've just sort of being asked, they're not getting up, they're swearing, behaviour, the parents need to turn up, that sort of stuff." (Aboriginal Liaison Officer)*

> *"Just letting the team know like if we get someone from remote we let the team know where this community is, how far the nearest hospital is because there's only usually clinics on the communities and so looking at things geographically and then like what their cultural background is because all Aboriginal cultures are different but same if you know what I mean. Yeah and just basically looking after them while they're here and making their stay comfortable and their journey here comfortable." (Aboriginal Liaison Officer)*

> *"We go there and just advocate on behalf of the Aboriginal patient and have feedback, it's in regards to the feedback, more of the patient." (Aboriginal Liaison Officer)*

> *"So when a family comes up for outpatients if they need a bit of extra support, they'll contact the social worker or myself." (Aboriginal Liaison Officer)*

Challenges at work*:* The lack of FNHWs employed was stated as an important contributing factor in not being able to deliver best practice burn care. FNHWs expressed their concerns that staff fatigue and subsequent assumptions resulted in multidisciplinary workers treating First Nations patients unjustly.

> *"So fatigue management also comes into it because then the staff get tired and a patient comes in as a new admission so that new admission is not treated as a new admission because it's easier to go, actually this patient reminds me of the last patient that came here and they weren't very engaged so straight away, and it happens, that's a natural response when someone's fatigued." (Aboriginal Health Practitioner)*

> *"… we need more Aboriginal people in here especially AHPs [Aboriginal Health Practitioners]. I can just see a whole system of AHPs working across the hospital, less money because we'd be doing things right from the start, not putting down any other profession it's not about that it's about delivering a service. You know when we look at customer service if we look at big corporations that make lots of money, what do they do, they really focus on what their target group want and need. That's what it's all about." (Aboriginal Health Practitioner).*

> *"I'm one to a whole division so no-one thinks to refer sometimes, maybe they're afraid to refer because they might be seen as not being able or culturally competent to deal with that patient. And so there's one of me to the division so that's very tricky most of the time." (Aboriginal Health Practitioner)*

7.5.3 Multidisciplinary burn team members' perspectives

Multidisciplinary burn team members have a varied understanding of the importance of the FNHW role. Perceived descriptions of the care provided by the FNHW role including meeting tangible and cultural support needs (Table 7.3).

Table 7.3: Multidisciplinary burn team member's perspectives and challenges

Tangible support	**Cultural support**	**Two worlds grappling**	**Challenges/work**
Fix problems such as absconding and surveillance Not understanding Education Network for aftercare appointments	Not appreciating needs of family and patient circumstances Communication	Understanding the importance of working together Perceived need for involvement Non-involvement in core Multidisciplinary team meetings	Not enough FNHWs Overworked

Tangible support: Multidisciplinary team members perceive the role of FNHWs is to provide families with tangible support including provision of education and networking for aftercare appointments. They also perceive the role is to stop people from absconding against medical advice.

> *"We don't have an Aboriginal Liaison Officer [ALO] at the moment because she's unwell but we are recruiting to a contract position and I would always take the ALO… with me to go on the first visit with a family, check the family, because I just think it's really useful and then we kind of divide the tasks so you know she might do some of the more liaison practical things and I will do the trauma stuff with the family and the assessment." (Social Worker)*

> *"I use them [Aboriginal Liaison Officer] all the time especially if patients abscond or I need to know more about family relationships like, do you know much about this mob or their family… And I also use them quite a bit when you're trying to arrange and negotiate appointments for outpatient clinics and where to from here." (Clinical Nurse Consultant)*

> *"… it is such a isolating environment down here, very different and I don't pretend to know how I can understand and address those things culturally*

and so I really look for their [FNHW] input so to try and get an understanding how the parents and the child's feeling and what their care needs are." (Consultant)

"We have one or two chronic rehabilitation patients post-burn who are Indigenous, they are very involved with the ALOs [Aboriginal Liaison Officers] and also very involved with social work in terms of helping to arrange transport particularly if they're from regional centres, to us and back from us." (Registrar)

Cultural support: Multidisciplinary team members perceive the role of the FNHW to include the provision of cultural support including an appreciation of family circumstance and communication. Some team members stated the importance of having FNHW involvement to ensure the family and child from remote communities felt comfortable.

"I've been in this hospital in different capacities over time from a very junior doctor to a registrar and now a consultant and I have noticed that there's been a difference in the input from our Aboriginal Liaison Officers and I'd like to see more input because when I was a junior doctor I remember them being there all the time on the ward with the families and you could really notice the comfort that families found from having cultural similarities with staff there." (Medical Consultant, Surgeon)

"We always make sure we get the Indigenous liaisons involved just simply because a lot of the time especially if they're coming from remote communities they may not have the family support and we know that family and community is a big thing for Indigenous people." (Occupational Therapist)

Two worlds grappling*:* Multidisciplinary burn team members understood the importance of working together and the need for FNHW involvement in burn care. However, there was evidence in the data that illustrated a lack of commitment towards involving FNHWs in burn team activities such as core multidisciplinary

meetings. At the same time often criticising that FNHWs are unable to effectively relay important family information.

"… I think both work, you can't have one [multidisciplinary team] without the other [FNHW] and I think probably there are ILOs [Indigenous Liaison Officers] being underutilised and under-resourced for the amount of demand that we have and certainly like the model of care in Queensland for our ILOs are more a supportive role, they don't take on a clinical caseload, they don't do hands on dressing changes or anything like that, they're more an emotional support and navigating the health system for the Aboriginal clients and Torres Strait Islander clients." (Occupational Therapist)

"I think the ideal thing would be to get Aboriginal staff involved in their management, they sort of identify better with Aboriginal staff, the difficulty is finding those who are trained well enough but they do seem to respond better to those than us telling them something." (Medical Consultant, Surgeon)

"… sometimes we have to get the Aboriginal Liaison person in if we're having difficulty communicating, especially the kids that come down… sometimes it's really hard to engage with them, and you've got to get help in for that sort of thing. The indigenous kids we tend to get here coming from… tend to be different." (Surgeon)

"I think their ability to communicate with the team has been lacking, maybe they're great at talking to the family but then feeding back and actually feeding our information back is probably, there's not a really strong link there. So from my perspective I think having stronger ALO [Aboriginal Liaison Officer] support, that liaison and educating me of what I need to do or how I can get through the other way, how can I get my message through via the ALO officer, probably involving them more would help in certain circumstances." (Physiotherapist)

"I guess one of the obvious ones is asking for support from our ILO [Indigenous Liaison Officer] to facilitate meetings or education or discharge planning or resilience sort of stuff, to be having that supported conversation with me so that I'm being culturally appropriate and culturally aware." (Clinical Nurse Consultant)

"We have Aboriginal Liaison Officers [ALOs] in the hospital and we're very quick to try and get them involved very early on but I think their capacity at times from my perspective has been, I think their ability to communicate with the team has been lacking, maybe they're great at talking to the family but then feeding back and actually feeding our information back is probably, there's not a really strong link there. So from my perspective I think having stronger ALO support, that liaison and educating me of what I need to do or how I can get through the other way, how can I get my message through via the ALO officer, probably involving them more would help in certain circumstances." (Physiotherapist)

Challenges at work*:* Multidisciplinary team members recognised there are challenges between FNHW availability and being over worked due to inadequate resourcing of First Nations workers. It was also recognised that poor interaction with FNHWs by the multidisciplinary team members impacted outcomes for First Nations children.

"When they're identified as Aboriginal or Torres Strait Islander we would always engage with the Aboriginal Health Officer… she's currently off at the moment and we don't have that service available to us." (Clinical Nurse Consultant)

"… wonderful, she's worth her weight in gold, but we need ten of her." (Physiotherapist)

"… occasionally we've got to get the Aboriginal and Torres Strait Islander Liaison Officer involved if it's a particularly sticky situation but most times we can deal with things in the usual manner." (Surgeon)

"I understand it's about getting them home and back into their environment and the financial strain and things like that about getting back but I feel we're very mindful of those sorts of things but what we're pushing is long term scar, long term loss of movement of arms and hands, you know for that sort of outcome, but I do think probably the relationship between her [Aboriginal Liaison Officer] and us [burns team] probably isn't ideal which maybe then impacts onto those children." (Surgeon)

7.6 Discussion

First Nations ways of knowing, being and doing in the context of health and healing are not always present within with the Western biomedical health systems that surrounds and informs initial burn care and burn aftercare. Multidisciplinary teams do recognise the importance of FNHWs, but systems are not set up to support resourcing because all categories said they're overworked. This further supports evidence about how the biomedical model excludes the lived experiences and knowledge of First Nations people (Fraser et al 2019). This lack of inclusion is partly the result of a discrepancy between the perspectives of First Nations families, FNHW, and multidisciplinary burn team members regarding different ways of health and healing. The First Nations families experienced improved cultural safety and were able to access necessary tangible support through care provided by the FNHW. This supports other studies (Chang et al., 2007) that have highlighted the necessary role of FNHWs in better being able to understand the needs of First Nations families. Similarly, FNHW experience of being involved in burn care for First Nations families was that they understand their contribution to care and wanted to be involved in the multidisciplinary care yet were excluded. While First Nations families and health workers experienced and understood these needs, the health systems informing multidisciplinary burn care excluded First Nations ways of knowing being and doing. This was evidenced by the team's exclusion of FNHW from team meetings, and by the Western biomedical models lack acknowledgement of the importance of the FNHW role and subsequent resourcing.

Different ways of knowing, being and doing exist. Values are often placed on needs without considering these differences. This is evidence of colonisation through a

disregard to different ways of knowing, being and doing. Care that is regardful of differences, improves dialogue and reduces power imbalances will lead to an experience of improved culturally safe care.

7.6.1 Two worlds collide

There was an expectation verbalised by FNHWs that some health professionals only used the FNHWs role as trouble shooters for assumed difficult patients and did not value the professional role of a FNHWs. However, the diverse nature of services for First Nations children and families was expressed as essential by family members. FNHWs provided cultural and spiritual care, tangible support such as transport to aftercare appointments, accommodation and food vouchers. Families valued the FNHW for alleviating fears, providing cultural safety and advocacy due to a shared recognition of cultural knowledge and connection.

Members from the multidisciplinary team merely asked for assistance from FNHWs when there was a 'problem to fix' such as absconding. Ongoing aftercare appointments were facilitated by FNHWs only when all else failed due to team members inability to reach the family for aftercare appointments. From the data collected from members from the multidisciplinary team it was apparent that FNHWs are not valued for the quality of care that families had expressed.

7.6.2 Colonisation

A power imbalance exists in favour of the Western biomedical model (Taylor and Guerin, 2019), especially as it relates to burn care for First Nations children in Australia (Fraser et al., 2018). Multidisciplinary burn team members showed power imbalances through their placement of value on the needs of First Nations families. Their values were assumptions, not grounded in evidence, and showcased the implicit bias within the system of multidisciplinary burn care. Furthermore, multidisciplinary burn team members sought input from FNHWs sometimes based on needs that were centred in a deficit mindset. For example, when they thought a First Nations family would not attend follow-up care due to dysfunction. The problematisation of First Nations

people's needs is indicative of structural racism in Australia's health system (Durey et al., 2012).

7.6.3 Cultural safety

Cultural safety has been shown to improve the health outcomes of First Nations people in accessing mainstream healthcare (Brascoupé and Waters, 2009; Javanparast et al., 2018). Furthermore, engagement in critical reflexivity in healthcare has been shown to support the competence of non-Indigenous healthcare professionals. Support for cultural competence in policy documents contributes further to improved cultural safety. Good cultural competence leads to an experience of culturally safe care. First Nations families and health workers understood the FNHW role in enhancing an experience of cultural safety, whilst multidisciplinary burn team members grappled to acknowledge the role's contribution to achieving quality care. So, while multidisciplinary burn team members said they understood they role, the disjuncture between the two ways of knowing being and doing supports the idea that enhanced cultural training is imperative for multidisciplinary team members to move beyond the divide and contribute constructively to closing to gap.

7.6.4 Strengths and limitations

Combining the two sets of data strengthens the reliability and validity of the issues surrounding FNHWs' crucial involvement in burn aftercare. Furthermore, this combining of data also resonates with the methodology used to inform sub-study two whereby Aboriginal ways of knowing, being and doing (Martin and Mirraboopa, 2003b) are integrated with the Western biomedical standpoint (Taylor and Guerin, 2019). It has also shown that by using Indigenous methods, which is instrumental in decolonising research approach that supports the empowerment of all Aboriginal and Torres Strait Islander peoples and communities in this study (Rigney, 2001; Smith, 2013).

A limitation of sub-study two was not asking if any multidisciplinary team member identified as a First Nations person. Sub-study one only yarned with children and their

family that were admitted to a tertiary burns unit and may have missed perspectives from families whose child with a burn was seen outside of the tertiary setting.

7.6.5 Conclusion

Delivery of culturally safe care is essential to ensure equitable health outcomes. This paper has highlighted the importance of inclusion of FNHWs in delivery of healthcare to Australia's First Nations children who need ongoing complex care. It is essential that FNHWs are active participants in the multidisciplinary care burn meetings and are encouraged and supported by the team members to engage in partnership of service delivery and ongoing aftercare for the child and family. This will require additional resourcing and additionally important changes to clinical hierarchies in the delivery of care, to ensure the important role of FNHWs is appropriately noted and rewarded.

7.7 References

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Chapter Eight: The Families' Stories

8.1 Introduction

In chapter seven we highlighted the importance of First Nations Health Workers in delivery of healthcare to Australia's First Nations children who need ongoing complex care. Chapter eight is central to my study and essential to this thesis it is where the voices of family members whose child had sustained a burn injury and their perceived barriers and facilitators to their child's and family's healing processes are told. Research in our communities, involving our people, has historically been told by non-Indigenous academics whose work has been analysed using Western methodologies. Each section has subheadings that have been used to convey the journey of each family and was agreed upon when the family and I analysed the data together. The analysis of the data and the family's involvement in the analysis of their stories is explained in chapter three.

First Nations people globally have been struggling to have their voices heard and only in the last decade are we seeing a shift from colonised research and the suppression of First Nations voices to decolonising research where our voices are being heard. Cultural integrity meant keeping my word to the families who wanted to tell their story, who wanted to be heard and who wanted to make a difference for other First Nations families whose child may one day also go through such a devastating injury, one that impacts families and communities. This chapter is dedicated to two families who asked for their voices to be heard. They tell of their journey from the moment of the burn incident through to the experiences of their aftercare.

You, as the reader, will be touched by the strength and resilience of families as they travel through the stories of their child's and family's experiences in our health systems. You are given an insight into the strength of Aboriginal culture and community connections that shows how families overcome the many barriers they face as they reach the end goal of health and wellbeing.

These stories have not had any grammatical correction and each voice is the true voice of the families. All names and places have been changed for the privacy of the families.

8.2 Robert's story told by his mother

8.2.1 The burn injury

Robert, he was six at the time, seven now and Tommy was nine. Well, I was asleep at the time and Robert and his nine-year-old brother were out playing around. My sister was in the lounge laying down watching TV and he was in the room putting hair gel or hair oil whatever on his hair, and Tommy the nine-year-old brother came and was flicking the lighter behind his hair three times, and the third time whoosh, just went up. I was crushed, it happening to him coming, flying out I just – I don't know how to feel I just – I was crying the whole time. He burnt his forehead, the top of his ears, his right hand, a bit of that were he tried to put his head out of the flames, at the time he was burning, and then the back of his – on his shoulders and along the back of his neck. But the shoulder and the neck wasn't so bad, just lightly burnt.

8.2.2 The trip

I drove him down to the hospital. Because they rang the ambulance in Broken Hill there, we're like how – how many kilometers? I'd say about five kilometers away from the hospital, yeah five. Anyway was going to wait for the ambulance but I said no, I don't know how bad these burns are, you know. I jumped in the car rushed him to clean up there, took him you know. Ambulance, they take a bit, because you can't blame the ambulance, because they've got to be careful how they drive to get to a person. But yeah, so I rushed him up and got him in, run straight into the emergency with him. And they were very helpful when they see me come through. Took him straight in, and yeah, got to him, put him in plastic, covering him, so there's no germs or whatever and the infection won't get to him. They just wrapped him, covered him over. And yeah, I just stayed overnight in the Hill and that morning was flying out at seven in the morning Sydney. They just said look we've got to fly him to Sydney and that's all they told me. I said oh, okay.

Me and my sisters were up at Broken Hill Hospital but like when we fly down just me and him came and then June flew down, just reaching Sydney you know, and knowing that we're going to be here for a while I just, and looking at him at this, wish it didn't happen you know, because you don't wish anything to happen to any kid really.

He's the only one major burns that we come down here and spent that nearly five weeks, six weeks.

8.2.3 The healing process

Broken Hill, no worries with them. They're my hospital. That's my home, yes. Anyway, they were good. The burns hospital just said they don't want to muck around and keep him back in Broken Hill in case it gets worse; that's why they flew us out to the burns hospital. As soon as I got here they let me know a few things about his burns and he'll swell up, but I didn't like the dressing part where they had to brush him; I didn't understand that. Yeah, they tell me stuff about him swelling up and then yeah, swell up then he'll start – because they had the pump and all the antibiotics so he doesn't feel so much pain because he was in pain.

Yeah, it hurt him and there's a few times where they wanted, from the start they wanted me to – they asked me if I wanted to leave the room while they did the dressings when he was awake. I said, "No." They said it can be very – you'll get stressed just looking at him being – feeling he's in pain. I mean, they gave him this medicine that is supposed to numb him a bit, and he wouldn't feel a thing, and I was like, bullshit. Couldn't have numbed him that much if my kid fucking screamed – oh, screaming the way he is, you know, and I said, "Are you sure you're doing it right?" I used to bath him. I said stop it and just wait and let him cool down and they said, "You need to leave, Miss," and I said, "I'm not leaving my kid. I'll stay here right through. I'm not leaving even to sit outside for a couple of minutes while you mob dress him, and what not. Just handle him, get it over and done with and go." I said, "No one's manhandling my boy." Yeah, didn't like that much. You know I wish they'd be a bit gentle with how they go because they're not the ones who're burnt. Or feeling all the pain and yeah like as parents we've got to watch and watch our kids go through that

pain. But yeah, no one doesn't want to be - no parents want to be put outside the room to let them handle your kids.

It would have been nice – I don't know – it would have been nice if they had been doing the dressing, putting him to sleep more often until it's healed a bit more because honestly, just watching them doing it you felt like jumping over and slamming them. "Let me do it. I've seen you mob do it over and over; I'll just be a bit more gentle."

Well at that start they told me I might be for at least three to four weeks depending on how the burns were, and then when they said, oh, the third week it was like, well you might be here for a couple of months. And that really sunk into my heart; I was like, I don't know.

It was a week before his father could came. The boy was so happy to see dad. I was happy when the father come and uplifted him right up. I said, "Junior, you've got a visitor," and father pops his head around the corner and, "Dad!"

And then I was thinking you know, is there any chance we're getting back to Broken Hill and staying in there and they can look after us there, at least we've got the family to visit us then more often, and I'm back there at least I would have swapped with the girls at my sisters, so yeah and then I would have moved home with the girls. But yeah we – yeah, no go until he was literally healed. I don't know why. No reason, they never told me why I couldn't go back to Alice.

Junior was getting wild with me because he couldn't go much places you know, I snuck him out, went for a ride. We said we'd go, you know, go down stairs for a walk, I'd take him for a ride. I took him to the beach. I didn't worry, as long as it made my kid smile. And that, you know his head was well covered with the dressings and everything and even put a pom pom on this hat, making sure it was covered, so he was well covered and yeah, I took him out as, you know, after he was allowed to run around and stuff and then I started asking the doctors can I go down to the – to the nice big green lawn there, so out of the hospital I said, "Can we just go across the road?" They said, "Okay, for an hour down there." It helped getting out of the hospital for a bit.

8.2.4 Effects on the child

Well after his burns and everything when we went back, he was okay because we told all the other cousins not to ask him too many questions and all that, all the other ones. And they understand and so that helped a lot. It didn't trigger anymore – there's times where he'd wake up and "Mum, I'm on fire" or if he's smelt smoke he thought it was his head burning. Because the smell of it yeah, just went right through the house at the time. It was like, give or take three to four months after his incident because not many kids, like I said got the little ones not to ask questions, all that flew past and it was really good. I helped him come night time I'd more or less let him play right through the day without even trying to have a little afternoon nap. Play and play as hard as you want, go for it son, run. And that's how I wearied him out so he'd have a good night sleep then and yeah, it was good. Very happy with my son how he has come so far and, but just a couple of months or about four months back he's been a bit of a fire bug. That's a another question I was asking does some kids, you know, when they do get burnt do they turn and want to play with fire or, because when he chucks paper in the fire you know we might have, we're having a barbeque or something he chucks a piece of paper and whoa, look how it burns you know?

His looks at his hair because he's always talked about growing his hair because Grandpa told him in the young days, Grandpa used to have nice long hair, so yeah, he just wants to grow his hair like Grandpa. And that's what's happening now, he's growing his hair. He's a different boy altogether. He's got it rough because, like I was telling you about the golden grandchild. Jealousy. All the granny's are jealous of little Robert only because he had his little accident grandpa's really more attached to him. So, yeah, it's a difficult time.

8.2.5 Effects on the family

Oh it was very hard because not many - like my two kids like they, the other two sons, I've got a nine year old and, I mean an eight year old and I've got a five year old, they love sleeping with me and then I had to have Robert because of his burns and keeping him all by himself and things like that and so there's a little war against my little three kids. With the family, they're a lot of help but yeah all other kids were getting

frustrated too that they couldn't touch him or things like that or play you know, rough with him. They'd get told off and - because it made a bit of argument between me and my brothers and sisters. And a lot of times where he felt sorry for himself because the kids didn't want to play with him, all his cousins. So that was another really hard thing. I got through over all the kids didn't want to play with him. "No we're not allowed to play with you we'll get told off," and things like that. And I said, tried to explain and yeah, so that was really tough on him, being burnt. And lonely, yeah. His mother had to take him into hospital and the clinic there where they stay in in the community and get him some sort of – try and help him with a bit of sleeping pills, or something, put him to sleep, because he used to get up and just cry for Robert and constantly trying to ring up and find out how Robert was and kept saying sorry over and over on the phone, and that was sad for me.

Tommy, my big sister's son. Her baby; that's her baby. So yeah, my big sister Ann, she said, "No, this boy's really broken, Sis." I said, "Yeah, poor darling." And I couldn't growl at him or anything for it. Any reaction when things go like that, I react real, like that, go off my head, but this time I didn't. My main concern was just grabbing Robert, chucking him – getting him to the hospital and then when little boy there Tommy just constantly crying and wanting to ring junior up I didn't bother growling or being nasty or "That's why he's here because of you," didn't say anything like that. I could feel what he was going through.

8.2.6 Racism

That hostel, well they put everything in my name, and I tried to explain to our hospital, "Can you tell them, because the father's coming over from west and we want to take turns and turns, so one week he might camp at the hostel, I'll camp in the hospital and then visa versa." Whether they explained that to them, according to the hostels here, their rules was it's your name, you have to stay here, and I found that very unfair. They're not trying to make us feel comfortable having shared times, giving my husband time out and me with my son. He stayed in the hospital the whole time. I was staying in the hostel. I didn't like it much. I wanted to be up there with my son. Kids all back on Country, the girls, and son up here with – son in the hospital with father and I was in

the hostel camping every night by myself. I felt lonely and they didn't take consideration on our family. Our three sisters and two brothers and all our kids from our siblings, all our nieces and nephews, they all call us mums and dads. There's three mums and two dads plus grandfathers and other mums. But we're a tight little group, but all Aboriginal families have all got that connection with kids.

No matter that's your – my big sister, that's your mum too, and so on and so on. You can have 10 mums; be the richest kid in the world.

Well I'd ring my girls – you could hear them crying to come to me, but you wish you could just cut yourself in half. But yeah, it would be nice if the girls were with me. Just, like I said, it would have lifted his spirit up. There's not many things here like that, organisations like even just home, if they were to send my kids with another sister of mine, keep me company too, no culture safety here.

You'd think these mob here in in the city would feel for us, outsiders that come in when coming in for this, what happened to our kids, and stuff like that, help us more. Because father couldn't even come and sit down with me even just for a few hours at the hostel with me, give me a bit of comfort while little junior's in the hospital sleeping, having his rest and nurses looking after him, I couldn't even have my husband there to sit with me and comfort me for a bit, and that was horrible. There's one old man that used to back home at the hospital; he was nice, and he said, "Yeah, tell your husband to come," but when the other workers were on, can't do it, "Can't do it. Can't let – he's not allowed in." I didn't understand that. Feel for us when we come a long way from home, from family, and that's all we want, is someone to sit with us and cry for our kids. But you don't have that here. They didn't like us being together like we would cause trouble or something.

8.2.7 Support back home

When we got home I didn't look for outside support, well me, myself, and my family, we just watched over each other and my family in that little hard time, they really helped me; gave me my rest, because they took time and my husband senior, he went

back – my little friend helped me a lot, and then, like I said, I told father, look at this boy, me and your three kids will come back over there sure enough. So all happy.

Would have been nice for them to follow up and ask how he's doing and all that stuff, because I sent to the city hospital I expected them to follow up and tell me if any changes or anything like that in his head and skin and look for them things. But yeah, nothing. No information about anything.

When I went back for a dressing in our home hospital they gave me some sort of gel to put on him. But it like - I didn't worry - I didn't take that as - I just went and grabbed the bush medicine. And it works. He's done a lot of healing, a lot of change. Well back in our place we have some sort of tree that we've got back at Utopia there. Oh it's everywhere, but yeah, back at home there. And yeah, our ladies all take the leaves off, break it down just boil it and they get bullock fat and have all that or sometimes they use the old pawpaw. But yeah sometimes mix it a little bit, but mainly with bullock fat and bush medicine itself because it's oily mix it together to give it that oily and smooth texture and yeah, nice smell about it.

I don't know, if I would have told them they might have said no, but I didn't worry. I wasn't going to tell them. I didn't – yeah, it didn't even come into my mind to ask them can I use bush medicine. I just took him home and used it.

8.2.8 What I wished happened

Come here knowing that I don't - I didn't know some things. So I was struggling too, trying to think, oh my god, how am I going to eat? He's all right. As long as he's all right, he's going to eat. I thought I haven't had a meal or you know. Little things that freak you out and you don't know and then you don't know how - whether to - how to get help.

I'd like help for families. If they could bring your family up and be one and that would be nice to have your kids with you at a time you're spending so long and the hostels around here to be more comforting with outsiders that come all the way. That would be really nice to just be fair and just okay let this happen, swap overs, things like that.

It doesn't care whose name, the room's getting paid for. I'd love that to, yeah, if they could help bring some your kid up, a couple of kids, little brother or sister to bring out. And yeah, if anything did like that did happen again it would be nice, really nice have family with them. Doing other - yeah. Be nice, helpful if family could come down with you because it helps, well, me and father - bubba Robert was really sad - we were just sad looking at each other. And sad - well I'm sad looking at him, what happened to him. So it would be nice to have family around, comfort.

Being here was hard - well knowing that I reckon if you're going to come to a different place like Adelaide/Melbourne/Sydney wherever you get sent you need to know things like meal-wise, all them sort of stuff. Because I didn't know you had come here and pay for your meals because back home in our hospital they look after the kids and the parents, make sure the parents happy, they feed the parents and the kids. And I mean you'd be natural if you look after your kids. You know we're coming in from communities; we're travelling from Country, I lived 247 kilometres north-west of the next city out in remote community. That's my community; my father's community: Utopia. And we travel down, been in hospital a few times with my kids, and well we get looked after, get fed. We don't have to worry about money and things like in our hospital I know it was 247 kilometres away but it was still our home hospital.

It would be nice if they could let a parent do the cleaning -bar of soap, yeah couldn't touch him and I know what they're doing and I've just watched for that whole nearly seven weeks when he was there, watching them how they done it. And if they just saying, "Do you want to wash him and clean him?" But yeah, or taught how to do it, that would have been nice if that would have been organised, knowing how to clean. Even if going to the local clinic and doing it there and dressing him and come back home. We drive to get his dressings done which takes us half an hour to where we live in a little homeland, our station, we have to drive nearly 30 ks just to get up to the local clinic and back. Yeah, how our community has only based shop, the council and we all live just about 17 or 16 out stations. It would be good to have a nurse come to do the dressings, I have to get someone to drive me and I don’t have money for petrol so I feel bad I can’t pay.

8.3 Mary's story told by her mother

8.3.1 The burn injury

I have four kids and my partner. We live in over a thousand kilometres away from a hospital. Recently my daughter Mary was burnt.

Mary was playing with her sister and another cousin in our old house and they've been playing with lighters and petrol and they were burning a tire and then - a flat, they've thrown more petrol on the tire and a flame has ignited. Mary has turned because she's seen the flames coming and then she's run but it was too late because it come up on the back of her shirt and then it's spread all up on her body and then she's run down the road still on fire and then luckily my sister and brother come out, seen Mary and she's run with the hose out onto the highway saying out to Mary, but Mary refused to go her, she was going to run back the other way.

And then she turned around and she's went over to her then. And then they stripped her clothes off, took her over into the yard and they just wet her with the water, hosed her down with the water. And then they rang 000 straight away.

And after that the fire brigade was first on the scene, then the ambulance and the police. And then Mary was rushed to our small town hospital but no one has come and notified us of Mary being burnt, any of the organisations. Mary's dad's uncle and aunty come and told us.

The police and the ambulance, you know they didn't inform us of it. You know it was Mary's dad's family who come and informed us of it half an hour later.

They come and picked us up and took us up to the hospital and we asked the reception if Mary was in there. They said yeah. So they let us into her and we found Mary on the bed with all of these wet cloths all over her body. Yeah, and then we just asked her what happened. He never notified us, the detective. When a detective had come along then. I forget his name. Yeah and the detective took me away into another room to do some investigation and I said, "Well they – I don't know nothing." And he said yeah well I don't know nothing there because he was called off playing football. Yeah so he's

just got off the field run home had a quick shower and straight to the hospital. And then the hospital told me, “Oh Rebecca you have to go home and get some clothes and that and you’re flying to a bigger hospital.” And I said, “Okay then.” So I’ve left with little Davy, me and Davy went back home, got clothes. I dropped him off at his nana’s house and then I returned back to the hospital. Then about 20 minutes later we left our home but before that the detective come out and met me outside and he asked me did I know what happened? And I said yeah Mary told me the full story what happened and I told him yeah they were playing with lighters, petrol and lit a tire up and then the flame come up, caught Mary and then she was burnt, she was lit on fire.

8.3.2 The trip

First Mary went in an ambulance with my sister to our hospital and then that night RFGS took us from our country hospital to the bigger hospital where we stayed for four days and because her burns, they estimated 35% but it was more than 35 it was 65% so then they rushed us by another plane to the city hospital with a burn specialist and that’s where she was until right up to May. And then after two and a half months we were discharged from there and transferred back to the second hospital we were in and we’ve been here since. Her dad stayed back with the other three. He come down once to the city hospital for a week and then went back home and then about five weeks ago he came here and stayed.

8.3.3 The healing process

The first hospital didn’t tell me anything they just said you’re going to a bigger hospital and that’s where we will be staying until yeah whatever happens. They was pretty good with her, gave her pain relief and that and they was on top of it and put all them things over her burns straight away.

But it wasn’t until I got to the city hospital where this burn Professor was doing all of her skin grafts and everything and he was telling me then what will be going on after that, yeah like all the further treatment and that. She was in a coma and then it was a month recovery so they took her out of the ICU and up into the wards and we was there doing a little bit of physio**.** This is hard for you, you get no rest, they just call you

up all the time for any little thing you have to walk back and forward you know. You have no chance to have a rest or anything.

Like when you try and come back and have a rest and that then they call you up, "Marys won't wake up, can you come over and wake her up, and can you help you know get her up?" And you know you've just come back or even dad comes back from the hospital then they ring five minutes later you know because they want us to be doing everything. Like they only come and do the obs and the tablets that's it.

Sometimes the only support is with dad and the kids. Like with Dad being here because he helps me do the dressings and he helps me shower her and doing her medications, yeah. But when I was in the hospital here it really wasn't any support because they just come and do her obs and do her tablets because Mary would say, "No I don't want yous to do my dressings I want my mum to do it," because she felt comfortable with me doing it instead of them doing it roughly with her.

I know what's going to happen now for the next probably 15 months, 12 to 15 months. Mary just keep doing her physio and OT to make her body and her muscles stronger. She has to wear these suits here, protection burn suits to make her burns like smoother.

8.3.4 Effects on the child

I've only got these two here and it's like Mary doesn't really understand yet like what's happened and that. She doesn't realise yet of the outcome of the burn and that and she doesn't talk about it you know and when you ask her she says, "No it's all right I don't worry about it." Yeah but later on down the track I think she will when she gets a bigger girl, yeah when she starts growing into a teenager side. Yeah because her reading, like her reading has gone backwards now. Before she used to be reading really good and now it's gone backwards.

Yeah she goes – she's got a school in the children's ward and there's two teachers there yeah but it's not like a normal big school. It's just like they only do certain hard work hey, a little bit of hard work and fun.

8.3.5 Effects on the family

Because I had other problems with family at home I had to come, like get closer to home so they let me come to the bigger hospital but it's still a thousand miles from home and we've been here ever since.

Our family is split up, we see Davy whenever we can make it to see him but Cheryl the big girl we haven't seen in a while hey, last time was that one week in the city that's the last time I've seen her that was four months, yeah it would be four months total. Cheryl, she's with her nana, that's Mary's dad's mother but she's going to the city in a boarding school. Davy is in town where we are now at a carer's place until we get a house. Yeah it has affected us a lot because it's like split us all up you know with the – with the other two being away separate from us. My other kids they're not taking it too good because you know they get upset and because you know they're not with us. And that they have to be away because you know we're doing this with Mary. They're not understanding it properly that you know Mary has to be here and she has to do her physio and that until she is strong enough and properly enough to do her own things, yeah like to the normal way she was before she got burnt. Yeah so we had to get up and move from our home town and transfer here somewhere.

It all just come really quick and fast and like we didn't expect we would be doing this for this long you know, not for this long.

We put Davy, his 10, in that carers place because you know he's got very bad language at the moment so but he doesn't really understand at the moment why he is away from us. The hospital house we staying at won't let him here with us because of his swearing but he has problems where still waiting been waiting years for the doctors to tell us what's wrong with his brain they think it could be turrets, that why he says I think. Cathy from child safety was saying that he's ten but he thinks like a three year old, he's like a three year old.

Well they're supposed be working on it and supposed to be getting counselling for him because of the impact of Mary but I don't know. Cheryl, she's pretty much all right back there with her nana yeah. Then I've got another lady, another teacher Spinifex

and CentreCare, and she's going to be escorting Cheryl down to the boarding school because she knows that we can't do it because we're with Mary and we have no car so it's good that she went out of her way in wanting to do something.

Davy sometimes he gets angry and he goes, "Yous are blaming me, yous are blaming me for Mary." Because he was with Mary when that happened. They got a counsellor out there that goes out and sees him every now and again. He had a mental assessment when he was in town, but yeah nothing come up that showed that he had a mental problem. Yeah but he just hides his things and he doesn't talk about it or let it out. Yeah and he was missing me as well when I was gone. Like he wasn't understanding properly why mum and Mary are gone for so long. We tried telling him but we have to go because Mary needs you know proper care and proper treatment. But you know he doesn't think properly like a normal kid would.

Then Davy thought that we gave him away that's what he's, that's the other thing he's thinking and we tell him, "We never gave you away. We're just waiting till we get this house and then you're coming back to us. But at the time because of your language you can't you know come and stay here where we're staying." We have to be here for the next 15 months for Mary to have continuous burn care. We've got to move from home and do everything now, we've got to transfer here. Dad was supposed to be back up home and cleaning the house, because someone broke in, the kids broke in there, just messed it up and done toilet all over the beds. Just messed it right up. So I was alone at the hospital again when he went. But now we are getting a house here in Town. We don't have our house back home anymore.

8.3.6 Racism

Ever since we landed in this children's ward I was warned about how we are treated different before I went in. And when I went in yes real sour the workers are sour. Yeah I've had a lot of arguments with the lot of them there and yeah they're just – don't want to help unless you know something goes wrong, because Mary is all right and then one night there was a light switch that was broken and I went to turn that light switch off but I couldn't because it was zapping green behind the thing so I left it

because I didn't get zapped and then the nurse came in that night and I said to the nurse, "Excuse me but this light is broken, you know we're not going to lay down with the light on all night, I have to get up 6:30 in the morning and get Mary ready." And she turned around and she said, "Well love you'll just have to get a sheet or a towel and just put it over your eyes." And I said, "Oh okay then thank you." And then yeah just had a big argument with them over that you know and then this nurse walks in and she was talking smart to me. She goes, "Oh the light's working you might have brains to go and do that, you might have got zapped you know." And I said, "That's why I didn't keep mucking around with it because it was going green." I said, "You know that's why I didn't bother touching it." And then she put on this big fuss and I just walked away from her and walked back in the room and shut the curtain and the doors. She thought I was dumb, didn't know anything.

Mary didn't want them doing anything to her because she thought that you know they might hurt her and she was using it in a like swearing way towards them and they just kind of thought no we can't deal with her. You know they all was like that, "No we can't deal with this kid," you know and like a couple times she was swearing really loud and they took the TV away from her to try and learn her and took her food away and put it out on the table outside. Took her lunch, got her lunch took it outside and put it on the table. And took the cable from the TV, took it away. And I said there was white kids in there doing that. And they was, really noisy with that. White children was in there and they was doing the same and their TV didn't go off nothing, they was allowed yeah.

Some of them young, some of them old but the old ladies are all right. The young ones are pretty you know smart yeah got attitude problems and sour faces**.** The nurses would follow me around thinking I was smoking in the toilet and I didn't, they hated family visiting Mary they had sour faces all the time when family come to see Mary. Then we try to change but we're still the same to everyone even the Priest they can just look at dad and say he's still the same you know we can never prove yourself.

8.3.7 What I wished happened

They should have come and told us you know as being the first on the scene and they should have asked you know yeah we know this kid we know the parents so we should go around and inform the parents. But instead they didn't choose to. No one had chosen to inform us you know straight away. Yeah they should have just sent us straight to big city hospital. Because I didn't know that they only deal with 10% burns here you see and they was only guessing, they had an estimate that he was 35. But it wasn't until we actually got to the burn people in the big hospital and then he come out of surgery and they said it was 65%. Like they'd need to better respect people you know because and help mainly with accommodation. But they need to better respect the parents you know of the children that's going through this because we've been through enough you know. All hospitals should have a place to look after burns so families don't have to go long ways to get that care and to be ripped from their everyday lives. Well, even just the physio that will make it easier, like if you've already got an OT up there at our home town that would be good. Like there's nothing major or big that he has to do now, there's just normal exercises and strengthening his hands and his arm to be straight, you know. That's all it is but we still can't do this at home we have to move from home just for this.

We were stressed right out from you know your kid nearly dying to helping your kid through the process of getting better and healing. You know you don't get enough sleep, you're eyes are - you sleep for about five hours probably, four hours at the most. You know they just need to start respecting parents and you know treat them kind. You know and not being sour to people, smiling at them and asking them are you all right, you know do you want help with that, you know or something like that. We miss back home, kids in school, fishing yeah, on the river fishing. Making tea with a billy can. It'd be like that and all the kids would be there too, fishing. Now that's all gone and they don't understand**,** Yeah, I don't want my family broken.

Chapter Nine: Discussion

9.1 Introduction

My research described in this thesis on the barriers and facilitators of burn aftercare for Australia's First Nations children is unique in many ways. Most importantly, it focuses on the voices of First Nations families' lived experience of their journey to healing after their child had sustained a serious burn injury. I have produced a rich body of work that provides a deeper understanding of the barriers and facilitators faced by Australia's First Nations children and their families when accessing burn aftercare in the Australian health system.

I have prioritised using Indigenous methodologies within my approach, consisting of yarning and Dadirri (Ungunmerr-Baumann, 2002; Walker et al., 2014), to allow me to connect with the child and their family in a culturally safe way that centres on the voice of the family. The approach that I adopted for this study was based on the strengths of an Indigenous research paradigm which enabled First Nations voices to be represented, acknowledged and valued. Importantly, First Nations families were active participants rather than objects of a study. Families were also able to contribute to the analysis of their own data in a cyclical method, which helped to minimise any bias on my part and also safeguarded the research by being respectful to the perspectives of First Nations families' journeys (Walker et al., 2014). There is a rich tapestry of my own standpoint throughout the thesis which draws on my own lived experiences as a First Nations woman, which has added intensity to my thesis.

When I first started working on this study and my PhD, the published research on Australia's First Nations people and burn injury was sparse and came only from Western Australia. The study in Western Australia was largely based on routinely collected hospital data (Duke et al., 2011a; Duke et al., 2011c). Subsequently, Möller and Ivers used linked hospital burns data from New South Wales, discovering that the prevalence of burns in First Nations children was significantly higher than for other Australian children living in remote areas (Moller et al., 2017; Möller et al., 2017a). This

paucity of research on burn aftercare with a multidisciplinary team reiterated to me the important need for more work in this area. This is therefore where my study lies.

9.2 Situating myself

Introducing and situating myself from the beginning of my thesis was imperative as it gives the reader an insight into my standpoint as a Gumbaynggir woman, an Australian First Nations person and a researcher (Geia et al., 2013b).

I also acknowledge that I am a descendent of an Australian mother whose ancestors were Anglo-Saxon. Nevertheless, I was raised in culture and on country as a daughter of a drover and the granddaughter of a strong First Nations woman and I identify as an Australian First Nations person.

My lived experience as a child included poverty, homelessness, domestic violence and racism. Education was not a priority in my life and I hardly attended school, I was border-line uneducated in Western academia. My education came from learning from the land and surviving. When I did attend school, I was bullied by teachers and other students, I wore clothes given to me from second-hand stores and rarely wore a uniform. When we were not droving, we moved around. I had lived in 16 different homes, all eventually condemned, over 13 years of my life. By the time I was 23 I had married, had three daughters, had divorced and was living in a refuge.

Giving up was never an option for me and I began my nursing career, starting as a nurse aid to finishing my degree in nursing. It was during this time in my life that I married again and had 2 more daughters, both of whom were born with disabilities. These disabilities required many long-term stays in hospital and years of outpatient appointments; my fifth daughter still has specialised treatments and is now 27 years old. My lived experiences of having children with chronic conditions and the trauma of watching my children go through many painful operations has given me a unique advantage of being able to connect with families whose child had sustained a serious burn injury.

It was due to my lived experiences in healthcare and lack of communication from healthcare providers, systematic racism, personal racism, disconnection from community and family separation that meant I found it easy to identify and connect with families.

It is common knowledge that research in First Nations people has not always been ethical, and exploitation of First Nations knowledges have happened in the past and in some instance still do today (Smith, 2013). To ensure my research remained ethically rigorous I followed the guidelines from the National Health and Medical Research Council ethical guidelines (Council, 2018).

It is because of my standpoint and everything that has shaped me in the way I think, feel and act within this world, that compelled me to ensure that my research was decolonised, and each family's voice would be heard.

9.3 Burns in children

Burns have been found to be a major cause of injury in First Nations children in Australia. The rate of hospital admissions is higher for burn injuries in First Nations children than for any other Australian child. Due to the complexities of burn injuries for First Nations children, the length of stay is longer than for other Australian children. First Nations children are more likely to need longer rehabilitation periods with multidisciplinary team involvement which will also affect the family (Möller et al., 2017b).

My thesis "Is Anybody Listening" contributes to the qualitative component of the larger NHMRC-funded study "Understanding burns in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes" (The Coolamon Study) being conducted by a research team based at The George Institute for Global Health.

The questions that guided this thesis were:

1. What are the barriers and/or facilitators to accessing burn aftercare for Australia's First Nations children and their families?

2. How can the barriers to burn aftercare be addressed in our health systems through the perspectives of the families of a child who had sustained a burn injury?

9.4 Finding the gaps

The first aspect of my work was to systematically review the literature to uncover what was known, and yet unknown. A systematic literature review focusing on First Nations children in Australia and the barriers they faced for burn aftercare presented me with no published papers. I then broadened the search to First Nations children globally with a chronic condition and their access to culturally safe aftercare (Chapter 4). Through broadening my search, I was then able to identify six eligible studies from Australia, New Zealand and Canada to include within my literature review.

Barriers revealed through my systematic review, I later discovered through my study, were still barriers present for burn aftercare today. Some, but not all barriers to access to ongoing care for First Nations children found in the systematic review included;

- Transport and financial difficulties
- Lack of cultural safety
- Miscommunication between multidisciplinary team members and family
- Lack of organised coordination between services
- No adequate burn aftercare plan in place
- Racism

Ameratunga *et al.* (2010) identified barriers to ongoing healthcare once a child had been discharged from a tertiary setting; key issues were lack of family support, lack of coordinated care between services and the lack of aftercare follow-ups. Investigation by Thomas *et al.* (2015) into how to improve health outcomes for First Nations children included a recommendation for culturally safe collaboration between health services and community members based on a holistic model of care. Cresp *et al.* (2016) evaluated hospital data on admission, emergency presentation and outpatient appointments, and found a need for cultural competency among service providers and a need for clear and concise discharge care plans to support families.

Findings suggest better health outcomes for children are achieved by engaging families with health services, improving communication between health service providers, and including First Nations service providers in the health plans of First Nations children. The holistic approach to healthcare recommended in the above papers would address the barriers identified above.

A scan of the policy environment found that although there is reference to improving cultural safety and experiences of racism and discrimination within the health system, there remains no specific focus on First Nations children and burn injury, and a lack of discussion on injury prevention in general (Chapter 2). There is a clear need for future policy to include a focus on burn related injury among First Nations children, as well as barriers and facilitators to aftercare.

9.5 Qualitative research

First Nations Research Assistants from the larger study were situated at the Children's Hospital at Westmead in New South Wales, Townsville University Hospital and Queensland Children's Hospital in Queensland, Royal Darwin Hospital in the Northern Territory and Women and Children's Hospital, Adelaide in South Australia. There were 18 First Nations children, including 59 family members, who took part in my study from South Australia (n=3), Northern Territory (n=2), Queensland (n=7), Torres Strait Islands (n=1) and New South Wales (n=5).

The Research Assistants identified First Nations families for my study through an invitation to participate. I was first introduced to the families and then accompanied by the First Nations Research Assistant from the sites to yarn with the families in their own communities and homes to ensure cultural safety.

My main aim was to empower the voices of Australia's First Nations children who required a multidisciplinary team for burn aftercare and their families. This was important to inform clinical practices to enhance the healing journey for the child and their family.

Through partnership of the child, their family and myself, we identified barriers to healthcare for First Nations children who had sustained a serious burn injury. Together we then documented the extent to which these barriers contribute to poor health outcomes in order to help inform the development of clear and practical clinical guidelines, and a strategy for their use in health services and community settings.

9.6 Is anybody listening?

9.6.1 Effects on child and family

There are not enough words to describe a serious burn injury in children. Some people explain it as horrific or traumatic for the child, yet a burn does much more than only affect the child who has sustained the burn injury. The siblings, parents, carers and other close family members are also affected by the child's injuries (Branche et al., 2008). Distance from appropriate burn care services means families are separated from other family members, and some families are dislocated from their communities. Financial burdens are placed on families due to the cost of travel, parking and living away from home expenses (Fraser et al., 2018).

There were many barriers faced by families in which they felt that health providers were not listening to them. Information was communicated poorly about the initial treatment and parents felt confused. Mistrust of medical staff grew, and families felt disengaged with their child's care. The lack of affordable accommodation was difficult for families coming from remote and regional communities and parking fees were exorbitant. Other barriers included the burden of caring for other siblings, compounded by a lack of services available to support childcare. Families reported isolation from their other children due to the lack of available accommodation for families to stay together, and therefore siblings were being billeted out to different extended family units. Barriers and issues such as these that occur during the acute phase become problematic in the aftercare phase.

Families felt they were abandoned by the burns unit once they were discharged, and with no clear plans in place, many were left with unanswered queries about what treatment was needed for their child's burn aftercare. Access to the burn aftercare

service with the multidisciplinary team proved expensive and many appointments were missed due to transport costs. Experiencing a lack of cultural safety, disempowerment and racism also led to mistrust of services.

9.6.2 Communication

Most families expressed a lack of input into their child's healthcare and frustration at not understanding medical terminology. The families saw the lack of understanding of what the health providers were telling them as a barrier and called it medical jargon.

The involvement of First Nations health workers working with other health providers and the child and family members was found to be an important facilitator in improving communication and family involvement in the child's ongoing healthcare. A specific example was ensuring appointments were attended post discharge.

Where there was an absence of culturally appropriate communication between service providers and family members, there was confusion and uncertainty about the care of the child. As Dahhan *et al*. (2012) showed in the model of care study, maintaining communication between the clinic and the family after discharge would improve relationships between the multidisciplinary team member, the child and the family. Valuable information and insights on burn aftercare provided prior to discharge would have improved burn aftercare processes.

9.6.3 First Nations health workers

A recent review on First Nations health worker contributions to quality care for First Nations people by Mackean *et al.* (2020) found that First Nations health workers improved quality indicators in primary health settings, although an urgent need for more research in acute care settings was identified.

There is a need for First Nations health workers to be involved in the burn care for First Nations children to cultivate a culturally safe place. In general, this inclusion would lead to better processes and communication around transport, financial difficulties, and organised coordination between families and multidisciplinary team members alleviating miscommunication.

Using a holistic approach to health for First Nations children and families by First Nations health workers means considering the needs of the family. Transport and financial help could alleviate the stress and burden faced by the child and their family, with the support of a First Nations health worker filling in the necessary forms to obtain assistance in these areas. For communication barriers around medical terminology, the First Nations health worker would provide support in these areas. Similar to that reported by Aspin *et al.* (2012), the families I spoke to also stated that having First Nations health workers visible and active in the management of their child's healthcare and family needs minimised the levels of anxiety, fear and confusion experienced.

Recognising and enhancing the importance of First Nations health workers in the care of children's burn care will alleviate many of the barriers faced by families in accessing burn aftercare.

9.7 Recommendations

This study has highlighted some very important issues surrounding aftercare of First Nations children with a serious burn. The study has also highlighted the potential for interventions which could improve access to culturally safe burn aftercare for the child and their families. These include:

- A new pathway
- Cultural competency
- Burn care plans
- First Nations health workers and,
- Alleviating travel and parking costs

These interventions are discussed below.

9.7.1 A new pathway

Through listening to the voices of the Australia's First Nations families, the findings stated in this thesis clearly show that families are seeking a culturally appropriate discharge model of care for their child who had sustained a serious burn injury. By

applying a coordinated pathway to accessing culturally safe burn aftercare, this will improve the quality of healthcare provision, communication gaps, transition from tertiary to primary care and optimal healing for the child.

Furthermore, including First Nations health workers in the burn care of the child and allowing them to work closely with families and multidisciplinary team members, will lead to an improved pathway on discharge for successful provision of ongoing burn care (Daws et al., 2014). If First Nations health workers were engaged from the point of admission to the transition to aftercare it would minimise missed appointments, improve the quality of burn aftercare and strengthen system effectiveness for First Nations families whose child needs burn aftercare (Christiaens et al., 2015).

9.7.2 Cultural safety

Cultural competency initiatives are embedded in health services throughout Australia, yet as long as these competencies are only recommended and not mandatory, culturally unsafe practices will continue throughout health services in Australia (Council, 2016). There is an obvious need for continued improvement in Australia's healthcare for cultural competency and safety for Australia's First Nations people. Health policies need to address cultural safety to improve access to health services, including burn aftercare. As I stated in section 6.8 "Recommendations" (page 85) the lack of culturally competent safety in communication has been shown to cause fear, distrust and anxiety, which was voiced both by the child and their family. Training for health workers is necessary to foster good communication, alleviate racism and stereotyping, which in turn will encourage families to engage in aftercare appointments (Haas, 2016). The continued culturally unsafe practices experienced by the children and their families further reinforces the institutional racism present in healthcare in Australia. Health services in Australia must incorporate culturally responsive healthcare as part of their routine burn aftercare if improvements in burn aftercare for First Nations families are to improve. Disconnection between the families and multidisciplinary team members, due to a lack of cultural safety for families disadvantages the long-term recovery of the child. Training health workers in culturally

responsive care ensures respect for First Nations children and families' needs in a vulnerable space.

9.7.3 Burn care plans

Developing a burn care plan that is enacted in a culturally appropriate and safe way must take into consideration the needs of all involved in the burn aftercare, including the multidisciplinary team, the First Nations health workers, the family and the child, in order to ensure a clear pathway for the child's aftercare needs. Using plans in this way will assist the family in understanding the processes in the healing journey and will lead to an easy transition to the multidisciplinary team from the burns unit achieving optimal healing for the child (Christiaens et al., 2015).

9.7.4 First Nations health workers

In this study, First Nations health workers had a positive influence on ongoing health and wellbeing of the children and families, as well as supporting the aftercare processes. However, the role of First Nations health workers in supporting families and having an integral role in burn aftercare has not been recognised in Australia's health systems to date (Cresp et al., 2016); (DiGiacomo et al., 2013). First Nations children who have experienced a serious burn and need a multidisciplinary team for ongoing aftercare to achieve a healthy, happy and productive life, would benefit from the continued support and involvement of First Nations health workers from point of admission through to healing.

9.7.5 Alleviating travel and parking costs

The United Nations Declaration on the Rights of Indigenous Peoples clearly states that First Nations people globally have the right to best practice healthcare no matter where their choice of residence is (Assembly, 2007). Australia's First Nations children also have the right to appropriate and beneficial aftercare for their burn injury to obtain the best outcomes for healing regardless of proximity to healthcare services. In Australia there are patient assisted travel schemes, yet the families I yarned with were unaware that this was an option for them, and families were not automatically asked if

they needed this assistance. The burn care plan should include information freely available to families concerning travel assistance and parking fee subsidies.

Collaborative and supported burn aftercare education and training for parents from experienced health workers will assist with home aftercare. Added access to a burns unit for any queries parents may have will alleviate the need for constant long-distance travel, and therefore families can remain together and reduce dislocation.

9.8 Conclusion

The compelling findings in my work show that currently, health systems and services in Australia (not including First Nations health services) are failing to meet the needs of First Nations children who have sustained a burn injury and lack support for their families. Throughout this thesis, families have voiced the negative treatment they have received from healthcare providers and provided evidence of a system that has failed to meet their needs. Health systems do not meet the needs of First Nations people and are not conducive to First Nations families' wellbeing. Policy and procedures must change and improve to provide the child and family with a holistic approach to healthcare for the child, and adequate support systems must be put in place for family members to engage in a culturally safe manner. First Nation Children who have sustained a burn injury and need ongoing burn after care would benefit from the involvement of First Nations Community Controlled Health Services in rural and remote setting. The disconnection between primary and tertiary sectors could be alleviated through the development of a culturally appropriate discharge planning model of care. There is a need for a First Nations care co- ordinator to connect families with specialist burn services and the enlisting the support of First Nation health services for families whose child had sustained a burn injury. This would ensure the well -being of the child and the family.

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Chapter Ten: A Note to the Reader

As I reflect over my last chapter, a note comes to mind that I want to leave with my readers. Bush fires are devastating our beautiful country. I would like to respectfully acknowledge the many people who have lost their lives, the families in their hundreds whose homes have been destroyed, the families displaced and thousands of animals that have perished. The world cries out for our Country, we cry for our Country and action is taken by many heroic people in our time of crisis. Ordinary people are stepping up to fight and change the course of these devastating fires and ordinary people are volunteering to help families rebuild their lives.

I am reminded that Australia is a great country, and in this country we have opportunities to make a difference. Dare I say that I am also just an ordinary person, like everyone else, wanting to make a difference, so I continue to cry out for equity in Australia's health systems using the power of Australia's First Nations families' voices whose child had sustained a burn injury. Although I may be repeating what many others have said and continue to say, I truly believe we must keep repeating ourselves, and repeating ourselves to those who can change policies, until consideration of those who are not heard are finally listen to and change is established.

Nevertheless, my knowledge in the area of burns in children previously derived only from what I had learnt in my nursing career, however through my PhD studies I have learnt a great deal more. Research now holds a different meaning to me from when I first begun working in this field. I have learnt that research is a personal journey and subjective to the researcher's standpoint. I no longer have negative views on research that is transparent, community driven and works in partnership with communities to improve health outcomes for First Nations peoples and communities. Over the last few years I have seen that decolonising research is growing stronger every year as more First Nations people take the leap into the research world.

There are many First Nations researchers conducting studies in communities who are challenging the Western-based research methods as my work has done. Therefore,

proving that research in First Nations communities can be more effective when First Nations people connect with First Nations researchers who have a lived experience and knowledge of culture, lore and Country connection. I have seen first-hand over the few years of my journey that First Nations people yarn more freely with other First Nations people; this is not new knowledge, it is a well-known fact.

Despite my journey as a PhD student in the world of academia, I have been able to stay grounded in who I am as a Gumbaynggir woman, a First Nations woman from Australia and as a mother, grandmother and great grandmother. I believe my cultural integrity has stayed intact as I continued to connect to my culture, my country and my community throughout my PhD journey. I am also the knowledge holder for my family. It is with utmost honour that I teach my children and their children our culture, taking them to sacred sites and telling the stories once told by our Elders, passed down from our ancestors. This is the essence of my life.

Appendix One: Participant Information Statement and Consent Form

the children's hospital at Westmead | THE UNIVERSITY OF SYDNEY | THE GEORGE INSTITUTE for Global Health

What's next for Aboriginal and Torres Strait Islander children after a burn injury? What are the barriers to appropriate care and well-being?

PARTICIPANT INFORMATION STATEMENT
(This Statement will also be verbally explained by the Aboriginal Research Officer to the participant)

What is research? What is the study about?
Research is a way we try to find out answers to questions. We want to learn about the best way to look after Aboriginal and Torres Strait Islander children when they have burns and are now back home.

Why have I been asked to take part?
We are asking all parents of Aboriginal and Torres Strait Islander children who had been admitted to a burns unit or hospital but are now back home that has had a burn to take part.

Did anyone else check the study is OK to do?
Before any research can happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is OK to do. This project has been checked by the National Human Research Ethics Committee.

Do I have to take part?
No you do not have to take part. You only take part if you want to. If at any time you don't want to do the research anymore, just tell let us know. You can still take part in the larger study.

What will happen to me if I take part in the research?
If you want to take part then you will be asked to answer some questions, called interviews. We will record your answers on a small recording device and may take a photo of you if you agree to it. We will use the photo to tell your story; only your first name will be used and with your permission we will show your photo when we talk about this project to other researchers, students and health care providers during presentations. Your photo will be stored on our servers at work which are password protected and we will keep the photo for 5 years when we will delete it from our servers. You don't have to have your photo taken if you don't want one taken.

Might something upset me when taking part?
We don't think you will be upset by anything when taking part, but if you ever feel unhappy or like you do not want to keep going, we will stop.

Will joining in help me?
Joining in will help us to better care for other children with burns.

Will anyone else know I'm doing this?
All the answers you give us will be kept private. Private means that no one but you, and the research person knows what was said.

Is there anything else you'd like to know about this research?

We are happy to answer any questions you have. You can ask us now or you can talk to the people who are running this research, their names are Julieann Coombes and Rebecca Ivers.

If you want to talk with Julieann or Rebecca the telephone and email address are:

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Prof Rebecca Ivers

Director, Injury Division

The George Institute

Tel: 02 8052 4341

Email: rivers@georgeinstitute.org.au

Or you can discuss your concerns with the Aboriginal Liaison Officer at this hospital.

Thank you for your time in reading this information sheet.

This Information Sheet is for you to keep. We will also give you a copy of the signed consent form.

THE GEORGE INSTITUTE for Global Health

THE UNIVERSITY OF SYDNEY

the children's hospital at Westmead

Professor Rebecca Ivers
The George Institute
PO Box M201 Missenden Road
Sydney, NSW 2050
Telephone: (02) 9657 0361
Email:
rivers@georgeinstitute.org.au
Web: www.thegeorgeinstitute.org

PARTICIPANT CONSENT FORM

(This Consent Form will be also be explained verbally to the Participant by the Aboriginal Research Officer)

I, ... (PRINT NAME), give consent to my participation in the research project **'Understanding burn injuries in Aboriginal and Torres Strait Islander children'**

I know/understand *(please tick the box):*

1. What I need to do at the interviews and the time it will take.	Yes	☐	No	☐
2. I have read the Participant Information Statement and have been given the opportunity to talk about the project with the Aboriginal Research Officer.	Yes	☐	No	☐
3. I understand that being in this project is up to me – I do not have to join in if I do not want to.	Yes	☐	No	☐
4. It is okay for me to stop being part of this project whenever I want to and I can continue being part of the larger study.	Yes	☐	No	☐
5. I agree to have my photo taken	Yes	☐	No	☐
6. I understand that my involvement is private and no information about me or my child will be published in any way that reveals who we are.	Yes	☐	No	☐

7. I understand that I am agreeing to an interview with the researcher to collect information and details of my child's burn treatment and care and the outcomes on our family life and to understand our needs and also the barriers to my child's health care now that we are back in our community.	Yes ☐	No ☐
8. I understand that if something upsets us during the consultations, the interview will be stopped, and we will be given the names of people we can talk to. If I have any questions to ask about the research, I can contact the principal researcher, the Chairperson or CEO of the local Aboriginal Community Controlled Health Service; or the Chairperson of the AH&MRC Ethics Committee as follows: The Chairperson AH&MRC Ethics Committee P.O. Box 1565 Strawberry Hills NSW 2012 Telephone: 9212 4777 Email: ethics@ahmrc.org.au.	Yes ☐	No ☐

Signed .....

Name:.....

Date: **……**

Appendix Two: Qualitative Yarning Guide

Attachment 9
Yarning guide

What's next for Aboriginal and Torres Strait Islander children after a burn? What are the barriers to appropriate care and well-being?

Hello, my name is Julieann and I'm from The George Institute for Global Health. I have enrolled in Sydney University to complete my PhD by research and these questions are part of the research I am doing to complete my studies. These questions are a small part of the bigger study ***Understanding burns in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes*** that you are already participating in.
Thank you for agreeing to talk to me about you and your child's journey in recovering from your child's burn injury. Just to remind you, this project is the first of its kind and involves four states – QLD, NT, NSW, and SA, and also has Aboriginal and Torres Strait Islander people working and contributing to every part of the study. It should only take about 30 minutes to complete.

If YES: **Interviewer:** Thank you for agreeing to take part. By telling your story the information can be used to ensure that all children get the best care available. In this interview we will be talking to both the parent/guardian and child. This will help us to describe the experience of burns injuries much better. We will be using a recording devise so that we capture your experiences in your precise words.

START INTERVIEW.

If person declines, thank them for their time, assure them that there will be no repercussions for not wanting to be part of the qualitative study, explain they are still part of the larger study and move on.

Impact on Family

1. How do you feel your child is recovering from the burn?
   ie: socially, physically
2. Can you tell me how has the injury affected your family?
   ie: financially,
3. Has anyone else in your family had a burn injury?
4. Does anyone help you with travelling or costs of your treatment or looking after the other children?
5. What do you think have been the barriers to the healing process?
   ie: travel, costs, distance
6. If you think back to the information you were given about caring for the burn once your child went home - can you tell me about it (describe the information – was there a DVD, brochure, letter, booklet etc) – do you feel it answered your questions (in what way) and was it culturally appropriate?
7. What would you have liked to receive?
8. What do you think other families would like?

Impact of Care

1. Can you tell me what support you have had now that you are home?
2. Is there anything you wish you could have changed about your treatment? ie: different or better
3. Did the clinic make any follow up phone calls to you?
4. Were these helpful and if you didn't receive any follow up phone calls would you have liked some?

Impact on Child

1. What frustrates you/your child the most about your treatment or the injury?
2. Did you/your child miss much school?
3. Has someone helped you/your child catch up on the school work you have missed?
4. Were you/your child given cultural support through this journey?

5. Looking back over this journey what would you or your child like to see changed?

END OF INTERVIEW

"Thank you for opening your homes to me and answering the questions I need to complete my studies and eventually my thesis. Your answers will help to guide protocols so that all Aboriginal and Torres Strait Islander children get the best care available."

Appendix Three: Ethics Approvals

AH&MRC ETHICS COMMITTEE

11th May 2016

Professor Rebecca Ivers

PO Box M201 Missenden Road

Sydney NSW 2050 Australia

Telephone +61 2 9657 0300

rivers@georgeinstitute.org.au

Dear Professor Rebecca Ivers

RE: 1032/14 - Understanding burn injuries in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes

Thank you for the providing an application for amendment of the above project to the AH&MRC Ethics Committee for approval.

Amendment requested:

Ms. Julieann Coombes addition to the project to conduct interviews with parents of children who sustained a burn injury and are now living back in their community.

The Ethics Committee has approved this request.

On behalf of the AH&MRC Ethics Committee,

Yours sincerely,

Production Note:
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prior to publication.

Val Keed
Chairperson
AH&MRC Ethics Committee

Supported by the NSW Ministry of Health

Location	Postal Address	Contact		ABN	
Level 3, 66 Wentworth Avenue Surry Hills NSW 2010	PO Box 1565 Strawberry Hills NSW 2012	Phone: Fax: e-Mail: web:	+61 (2) 9212 4777 +61 (2) 9212 7211 ahmrc@ahmrc.org.au www.ahmrc.org.au	ABN	66 085 654 397

CHILDREN'S HEALTH QUEENSLAND
HOSPITAL AND HEALTH SERVICE
HUMAN RESEARCH ETHICS COMMITTEE

Professor John Pearn (Chair) 3069 7228
Mrs Amanda Smith (Co-ordinator) 3069 7002

Queensland Government

Level 7, Centre for Children's Health Research
Lady Cilento Children's Hospital Precinct
62 Graham Street, South Brisbane QLD 4101
Telephone (07) 3069 7002

19th May 2016

Professor Rebecca Ivers
c/ Julieann Coombes
Project Officer, Aboriginal Health Ageing
The George Institute for Global Health
PO Box M201
Missenden Rd
Sydney, NSW 2050

Dear Professor Ivers,

HREC Reference number: HREC/14/QRCH/328
Project title: Understanding burn injuries in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes.
Amendment number: HREC/14/QRCH/328/AM02

Many thanks for your letter of the 5th May regarding amendments to the above **project. This has now been** reviewed and I am pleased to advise that the amended documents reviewed and approved were:

Document	Version	Date
Covering Letter		5 May 2016
Qualitative Follow-Up Interview Part 2	1.0	4 May 2016
Protocol		3 May 2016
Parent Information Statement - LCCH	3.0	4 May 2016
Participant Information Statement	1.0	4 May 2016
Participant Consent Form	1.0	4 May 2016

The Children's Health Queensland HREC is constituted and operates in accordance with the National Health and Medical Research Council's *"National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007)* and the *"CPMP/ICH Note for Guidance on Good Clinical Practice"*.

A copy of this letter must be forwarded to the Research Governance Officer. It should be noted that all requirements of the original approval still apply.

Yours sincerely,

Production Note:
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prior to publication.

Professor John Pearn
Chair
Children's Health Queensland
Hospital and Health Service
Human Research Ethics Committee

Cc: Ethics Committee

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menzies
school of health research

Postal: PO Box 41096, Casuarina NT 0811, Australia
Location: John Mathews Building (Bldg 58),
Royal Darwin Hospital Campus, Rocklands Drv, Casuarina NT 0810
Ph: (08) 8946 8600 Fax: (08) 8946 8464
Website: menzies.edu.au
ABN: 70 413 542 847

Ethics Administration Office
File Reference Number: HREC-2014-2214
Phone: (08) 8946 8687 or (08) 8946 8692
Email: ethics@menzies.edu.au

8 June 2016

Professor Rebecca Ivers
Injury Division
The George Institute for Global Health
PO Box M201
Missenden Road
Sydney NSW 2050

Dear Professor Ivers,

HREC Reference Number: 2014-2214
Project Title: *Understanding burn injury in Aboriginal and Torres Strait Islander children*

Thank you for taking the time to respond to the issues raised by the Fast Track Committee of this HREC. The amendment to the above project submitted on 05/05/2016 has now been approved by the Chair and will be ratified at the next meeting of the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (HREC). Please note that this approval applies only to research conducted after the date of this letter.

The following amendments are approved:

- **Stage 2 of the burns study:-**
  - **Aboriginal Research Officer (Ms Julieann Coombes) will conduct interviews with parents of children who sustained a burn injury and are now living back in their community.**
  - **Five interviews will be conducted in each state (NSW, Queensland, Northern Territory, and Adelaide).**

The following documents are approved:

Document	Version	Date
Safety Protocol Burns	-	03 May 2016
Understanding burns - Parent Information Statement – Royal Darwin Hospital	3.0	04 May 2016
Qualitative Follow Up Interview - Part 2 – Understanding Burns in Aboriginal Children	1.0	04 May 2016
The Royal Darwin Hospital – Understanding burn – Part 2 - Information Statement	1.0	15 February 2016
RDH Understanding burns - Part 2 – Consent Form	1.0	29 March 2016

Please note that all requirements of the original ethical approval for this project still apply.

As a reminder, the approved project timeline is: ***17/10/2014 – 31/01/2019***. An annual progress report or final report is required on or before the ***17/10/2016.***

APPROVAL IS SUBJECT TO the following conditions being met:

1. The Coordinating Principal Investigator will **immediately report anything that might warrant review** of ethical approval of the project.

2. The Coordinating Principal Investigator will notify the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (HREC) of any event that requires a **modification or amendment to the protocol or other project documents** and submit any required amendments in accordance with the instructions provided by the HREC. These instructions can be found on the Menzies' website.

3. The Coordinating Principal Investigator will submit any necessary reports related to the **safety of research participants (e.g. protocol deviations, protocol violations)** in accordance with the HREC's policy and procedures. These guidelines can be found on the Menzies' website.

4. The Coordinating Principal Investigator will **report** to the HREC **annually** and notify the HREC when the project is completed at all sites using the specified forms. Forms and instructions may be found on the Menzies' website.

5. The Coordinating Principal Investigator will notify the HREC if the project is **discontinued at a participating site before the expected completion date**, and provide the reason/s for discontinuance.

6. The Coordinating Principal Investigator will notify the HREC of any plan to **extend the duration of the project past the approval period listed above** and will submit any associated required documentation. The preferred time and method of requesting an extension of ethical approval is during the **annual progress report**. However, an extension may be requested at any time.

7. The Coordinating Principal Investigator will notify the HREC of his or her **inability to continue as Coordinating Principal Investigator**, including the name of and contact information for a replacement.

8. The safe and ethical conduct of this project is entirely the responsibility of the investigators and their institution(s).

9. Researchers should immediately report anything which might affect continuing ethical acceptance of the project, including:

- Adverse effects of the project on participants and the steps taken to deal with these;
    - Other unforeseen events;
    - New information that may invalidate the ethical integrity of the study; and
    - Proposed changes in the project.

10. Approval for a further twelve months, within the original proposed timeframe, will be granted upon receipt of an annual progress report if the HREC is satisfied that the conduct of the project has been consistent with the original protocol.

11. Confidentiality of research participants should be maintained at all times as required by law.

12. The Patient Information Sheet and the Consent Form shall be printed on the relevant site letterhead with full contact details.

13. The Patient Information Sheet must provide a brief outline of the research activity including: risks and benefits, withdrawal options, contact details of the researchers and must also state that the Human Research Ethics Administrators can be contacted

(telephone and email) for information concerning policies, rights of participants, concerns or complaints regarding the ethical conduct of the study.

14. You must forward a copy of this letter to all Investigators and to your institution (if applicable).

This letter constitutes ethical approval only. This project cannot proceed at any site until separate research governance authorisation has been obtained from the CEO or Delegate of the institution under whose auspices the research will be conducted at that site.

Should you wish to discuss the above research project further, please contact the Ethics Administrators via email: ethics@menzies.edu.au or telephone: (08) 8946 8687 or (08) 8946 8692.

The Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research wishes you every continued success in your research.

Yours sincerely,

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Dr Lewis Campbell
Chair
Human Research Ethics Committee
of the Northern Territory Department of Health
and Menzies School of Health Research
NHMRC Registration No. EC00153
http://www.menzies.edu.au/page/Research/Ethics_approval/

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*. The processes used by this HREC to review multi-centre research proposals have been certified by the National Health and Medical Research Council.

menzies.edu.au

The Sydney children's Hospitals Network
care, advocacy, research, education

Contact for this correspondence:
Research Ethics Office
Research Ethics Administration Assistant
Phone: (02) 9845 1253
Facsimile: (02) 9845 1317
Email: SCHN-ethics@health.nsw.gov.au

Corner Hawkesbury Road
and Hainsworth Street
Locked Bag 4001
Westmead NSW 2145
Sydney Australia
DX 8213 Parramatta
Tel +61 2 9845 0000
Fax +61 2 9845 3489
http://www.schn.health.nsw.gov.au/
ABN 53 188 579 090

3 May 2016

Professor Rebecca Ivers
Paediatric Surgery
The Children's Hospital at Westmead

Dear Professor Ivers,

HREC Reference: **HREC/13/SCHN/440 (Student Sub-project 1)**

Project title: **Understanding burn injuries in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes**

Site/s: **The Children's Hospital at Westmead**

I acknowledge receipt of your project amendment submitted 16 March 2016, requesting approval for:

> **Stage 2: Qualitative research component examining the barriers and facilitators Aboriginal and Torres Strait Islander children and their families face once they have left the burns unit and are now living back home in their communities. The qualitative research will inform Julieann Coombes' MPhil studies.**

The amendment/s was reviewed at the meeting of the Executive Committee of the Sydney Children's Hospitals Network Human Research Ethics Committee (SCHN HREC) at its meeting held on **6 April 2016** and subsequently by the SCHN HREC Executive on the **27 April 2016**.

I am pleased to advise that the documents reviewed and approved at the meeting were:

Documents Reviewed	*Version*	*Date*
Amendment Form		2 March 2016
Cover Letter		15 February 2016
Parent Information Sheet	V3.0	3 March 2016
Participant Information Sheet (12-16yrs)	V4.0	20 April 2016
Participation Information Statement – Part 2	V2.0	20 April 2016
Participant Consent Form – Part 2	V2.0	20 April 2016
Semi Structured Interview Schedule – Part 2	V1.0	15 December 2015
safety protocol home visit		18 April 2016
Cover Letter to SCHN HREC		20 April 2016

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The Sydney children's Hospitals Network

care, advocacy, research, education

This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Research Involving Humans* and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*

This letter constitutes ethics amendment approval ONLY. A copy of this letter must be forwarded to the Research Governance Officer at each site for governance approval.

This application has been assessed in accordance with, and meets the requirements of the National Statement on Ethical Conduct in Human Research (2007).

Should you require any further information, please do not hesitate to contact the Research Ethics Office at SCHN-ethics@health.nsw.gov.au or on (02) 9845 1253.

Yours sincerely,

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Dr Peter Cooper
Chair, Sydney Children's Hospitals Network Human Research Ethics Committee
Sydney Children's Hospitals Network Human Research Ethics Committee
Cc Julieann Coombes

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14/QTHS/209_8
Human Research Ethics Committee
Townsville Hospital and Health Service

Queensland Government

Townsville
Hospital and Health Service

11th May 2016

Prof Rebecca Ivers
PO Box M201
Missenden Road
Sydney, NSW 2050

Dear Prof Ivers,

HREC reference number: HREC/14/QTHS/209
Project title: Understanding burn injuries in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes

Thank you for submitting an amendment for the above mentioned study on 05/05/2016.
The correspondence was reviewed at the meeting of the Chairperson held on 11/05/2016.

The amended documents reviewed and approved at the meeting were:

Document	Version	Date
Notification of amendment: *Approval for Stage 2 sub study documents for parents*		05.05.16
Parent Information Statement	3.0	04.05.16
Part 2 Information Statement	1.0	15.02.16
Part 2 Consent Form	1.0	04.05.16
Qualitative Follow Up Interview Part 2	1.0	15.12.15
Safety Protocol Burns		03.05.16

The Townsville Hospital and Health Service HREC is constituted according to the National Health and Medical Research Council's '*National Statement on Ethical Conduct in Human Research*' (NHMRC, 2007). The Townsville Hospital and Health Service HREC operates in accordance with the *'Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research'* (NHMRC, 2003); and the '*National Statement on Ethical Conduct in Human Research*' (NHMRC, 2007).

Please notify the Research Governance Office/r at each site of the amendment, and provide a copy of this letter with a copy of the supporting documents as listed above.

It should be noted that all requirements of the original approval still apply.

Kind regards,

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Dr Nikola Stepanov
Chairperson
Townsville Hospital and Health Service
Human Research Ethics Committee

Townsville Hospital and Health Service
Human Research Ethics Committee
Telephone +617 4433 1440
Email TSV-Ethics-Committee@health.qld.gov.au

Research Support Unit
Phone: +617 4433 1351
File Number: SSA/15/QTHS/104
Our Reference: dbs/ethics/RGO/2015/104_3

Queensland Government

Townsville
Hospital and Health Service

Prof Rebecca Ivers
The George Institute for Global Health Australia
PO Box M201
Missenden Rd
Sydney NSW 2050

rivers@georgeinstitute.org.au

Dear Prof Ivers

HREC Reference Number: Hrec/14/Qths/209
SSA Reference Number: SSA/15/QTHS/104
Project Title: Understanding burn injuries in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes.

Thank you for your letter dated 5 May 2016, received 9 May 2016, submitting an amendment for the above research project.

I am pleased to inform you that authorisation has been granted for this study amendment to take place at the following site(s):

The Townsville Hospital

We note receipt of the following documents for our records:

Documents	Version	Date
Notification of Amendment: - *Approval of Stage 2 sub study documents for parents*		09.05.16
Parent Information Sheet	3.0	04.05.16
Part 2 Participant Information Statement	1.0	15.02.16
Part 2 Consent Form	1.0	04.05.16
Qualitative Follow Up Interview Part 2	1.0	15.12.15
Safety Protocol Burns		03.05.16
THHS HREC Approval Letter		11.05.16

It should be noted that all conditions of the original authorisation continue to apply.

Should you require any additional information, please do not hesitate to contact me on (07) 4433 1351.

Yours sincerely

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Sue Jenkins-Marsh
Research Governance Officer
Townsville Hospital and Health Service
6 /6 /2016

Townsville Hospital and Health Service
Research Support Unit – IMB 52
100 Angus Smith Drive, Douglas QLD 4814
PO Box 670, Townsville QLD 4810
Telephone +617 4433 1351
Website http://www.health.qld.gov.au/townsville/

Women's & Children's Hospital

Research Secretariat
Level 2, Samuel Way Building
72 King William Road
Tel 08 8161 6390
Tel 08 8161 6521
www.wch.sa.gov.au

7th July 2016

Prof R Ivers
The George Institute for Global Health
Injury Division
PO Box M201, Missenden Rd
SYDNEY NSW 2050

Dear Prof Ivers

Re: Understanding burn injuries in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes. HREC/14/WCHN/65.

I refer to your letter dated 5th May 2016 and to an email from Ms Coombes dated 25th May 2016. I also refer to a telephone conversation between Dr Zutlevics, the Chair of the WCHN Human Research Ethics Committee, and Ms Coombes on 14th June 2016 in which it was clarified that it is proposed that Phase 2 will have two parts – part 'a' covering models of care (approved 14th April 2016) and part 'b' involving follow up of families in their communities.

At its meeting on 22nd June 2016, the WCHN Human Research Ethics Committee approved the proposed amendment and the following documents:

- Adelaide_Information Statement_Part 2_version 1.0_04.05.2016
- Adelaide Consent Form_Part 2_version1.0_04.05.2016
- Safety Protocol Burns 03 05 2016
- Qualitative Follow Up Interview Part 2_Understanding Burns in Aboriginal Children Version 1.0_04.05.2016

Yours sincerely

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PETER ANDERSON (PROF)
A/CHAIR
WCHN HUMAN RESEARCH ETHICS COMMITTEE

Cc: Ms J Coombes, The George Institute for Global Health

Government of South Australia
SA Health

Appendix Four: Other Published Papers

Open Access Protocol

BMJ Open

Understanding burn injuries in Aboriginal and Torres Strait Islander children: protocol for a prospective cohort study

Rebecca Q Ivers,[1,2] Kate Hunter,[1,3] Kathleen Clapham,[4] Julieann Coombes,[1] Sarah Fraser,[2] Serigne Lo,[1] Belinda Gabbe,[5] Delia Hendrie,[6] David Read,[7] Roy Kimble,[8] Anthony Sparnon,[9] Kellie Stockton,[8] Renee Simpson,[7] Linda Quinn,[9] Kurt Towers,[10] Tom Potokar,[11] Tamara Mackean,[12] Julian Grant,[2] Ronan A Lyons,[13] Lindsey Jones,[14] Sandra Eades,[15] John Daniels,[4] Andrew J A Holland[14,16]

To cite: 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**:e009826. doi:10.1136/bmjopen-2015-009826

► Prepublication history for this paper is available online. To view these files please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2015-009826).

Received 27 August 2015
Revised 17 September 2015
Accepted 21 September 2015

For numbered affiliations see end of article.

Correspondence to
Professor Rebecca Ivers;
rivers@george.org.au

ABSTRACT

Introduction: Although Aboriginal and Torres Strait Islander children in Australia have higher risk of burns compared with non-Aboriginal children, their access to burn care, particularly postdischarge care, is poorly understood, including the impact of care on functional outcomes. The objective of this study is to describe the burden of burns, access to care and functional outcomes in Aboriginal and Torres Strait Islander children in Australia, and develop appropriate models of care.

Methods and analysis: All Aboriginal and Torres Strait Islander children aged under 16 years of age (and their families) presenting with a burn to a tertiary paediatric burn unit in 4 Australian States (New South Wales (NSW), Queensland, Northern Territory (NT), South Australia (SA)) will be invited to participate. Participants and carers will complete a baseline questionnaire; follow-ups will be completed at 3, 6, 12 and 24 months. Data collected will include sociodemographic information; out of pocket costs; functional outcome; and measures of pain, itch and scarring. Health-related quality of life will be measured using the PedsQL, and impact of injury using the family impact scale. Clinical data and treatment will also be recorded. Around 225 participants will be recruited allowing complete data on around 130 children. Qualitative data collected by in-depth interviews with families, healthcare providers and policymakers will explore the impact of burn injury and outcomes on family life, needs of patients and barriers to healthcare; interviews with families will be conducted by experienced Aboriginal research staff using Indigenous methodologies. Health systems mapping will describe the provision of care.

Ethics and dissemination: The study has been approved by ethics committees in NSW, SA, NT and Queensland. Study results will be distributed to community members by study newsletters, meetings and via the website; to policymakers and clinicians via policy fora, presentations and publication in peer-reviewed journals.

Strengths and limitations of this study

- The study has support from peak Aboriginal health bodies, and data will be collected by Aboriginal research assistants or staff with significant experience working with Aboriginal people.
- The study will include detailed measures of cost of care as well as functional outcomes in Aboriginal and Torres Strait Islander children sustaining serious burns; data not previously collected.
- The unique collaboration between Indigenous and non-Indigenous researchers, clinical and policy stakeholders, and community members will ensure strong translation to practice.
- The study will only identify children who are treated at tertiary burn units.
- There is a high chance of loss to follow-up, although this will be mitigated by data linkage.

INTRODUCTION

Burns are an important cause of injury in children in Australia. More than one-third of those affected by thermal injury in 2009–2010 were children aged 0–14 years, with 27% those aged 0–4 years and 10% aged 5–14 years. The Australian Institute of Health and Welfare (AIHW) reported that in 2009–2010, there were 2220 children hospitalised for burn injury across Australia. Burns are serious injuries; 13.3% of all cases of burns have a high threat to life,[1] with one-quarter of hospitalised patients for burns found to have hospital stays of at least 1 week, testament to their serious nature.[2]

Aboriginal and Torres Strait Islander children are hospitalised for burns and scalds twice as often as for other children.[3]

BMJ Open: first published as 10.1136/bmjopen-2015-009826 on 13 October 2015. Downloaded from http://bmjopen.bmj.com/ on February 29, 2020 by guest. Protected by copyright.

Although there are few research studies or reports describing burns in Australian children, the Burns Registry of Australia and New Zealand shows that, of the patients admitted to Australian burn units, 11% of paediatric patients identified as Aboriginal or Torres Strait Islander in 2013–2014.[4] The rate of burn injury per 100 000 population was also substantially higher for Aboriginal and Torres Strait Islander people overall compared with the rest of the population at 14.4/100 000 vs 6.1/100 000.[1]

As burns treatment itself can often be very painful and protracted, it is important to ensure families are adequately supported through what can be both a complex and traumatic process. While there are Aboriginal liaison units at most tertiary paediatric hospitals, it is unclear how well patients are supported with culturally appropriate and supportive care either in the hospital, or once they have left the hospital setting. Burn units report regularly losing contact with Aboriginal or Torres Strait Islander patients discharged to locations away from urban areas, although there has been no systematic analysis to assess how often this occurs. The accessibility of high-quality care to Aboriginal children, who constitute a high proportion of burn patients, particularly those from regional and remote settings, is particularly important, given the complexity of long-term burn care, where access to appropriate treatment is essential to produce good long-term outcomes.[5]

There are documented gaps in access by Aboriginal people to healthcare, both in primary care settings and in tertiary care. Aboriginal community-controlled health services are important in providing appropriate primary care, and there has been an emphasis on prioritising access to primary care of Aboriginal people to maximise prevention opportunities for chronic and other conditions. Nonetheless, there have been numerous studies highlighting the delays for Aboriginal people in accessing hospital care (suggestive of problems with the interface between primary care and the acute sector) for a variety of health conditions.[6] Additionally, gaps in understanding of the care of Aboriginal people once they are discharged from hospital, including how they access medications prescribed and how the cost of prescribed care acts as a barrier to receipt of such care.[6] Despite the development of Aboriginal liaison units in hospitals, while cultural security and cultural respect remain fundamental principles for Aboriginal Community Controlled Health Services (ACCHS), it is not clear how often these are achieved in other health services, which may inhibit their use by Aboriginal people.

Measuring the outcomes and costs of burns

Advances in all aspects of critical care and surgical technique have ensured that most children now survive their burn injury. Increasingly, therefore, the critical lens has moved from survival to morbidity, with one of the most important issues the prevention of long-term functional loss. The components that characterise long-term loss of function and disability in burn patients can include scarring, itch and pain, as well as a range of other elements including health-related quality of life, and psychosocial outcomes. There is, however, limited research evaluating such outcomes in children sustaining burns. The main studies are from US populations,[7] which may have some relevance to the broader community in Australia, but are very unlikely to represent the experiences of Aboriginal or Torres Strait Islander children. In US populations, Sheridan *et al*[8] showed that in children surviving massive burns, factors that were related to better outcomes as measured by various domain scores on the 36-item Short Form Health Survey (SF-36) scale include family functional status, early reintegration into usual activities and consistent clinic visits. A recent study highlighted the importance of family characteristics on recovery from burns.[9] Given that Aboriginal and Torres Strait Islander children are significantly over-represented in burns, are more likely to be living in out of home care[10] and may experience difficulty in accessing healthcare services for a variety of reasons, understanding care received, functional outcomes and their relationship, are crucial to development and implementation of appropriate care.

Further, while there is a consensus that the cost of treating patients with burn injury is expensive, little is known about the true cost of a burn.[11–13] In 1993–1994, burns were found to account for 2% of the total cost of injury, poisonings and musculoskeletal disorders.[14] A later study investigated health system and total cost of injury in Western Australia by age: burn injured casualties of less than 20 years old accounted for 43% and 37%, respectively, of the total cost of burn injuries.[15] A recent Australian study[12] found acute costs for an average adult burn patient were AU$71 000 with percentage of total body surface area (%TBSA) injured the primary determinant of cost. This is likely to represent a small proportion of the total cost of burn injury and treatment, with burn injuries incurring significant longer term costs following initial acute admission.[16] There is no research in Australia examining the cost of burns in Aboriginal children, or cost-effectiveness of various modes of treatment.

The objective of this study is to describe the burden of burns, access to care and functional outcomes in Aboriginal children with serious burns; in conjunction with burn clinicians, health services and Aboriginal community representatives, these data will be used to inform the development of appropriate, best practice, models of care. Specific aims are to: (1) describe the impact of burns in Aboriginal and Torres Strait Islander children; (2) describe the treatment received and its cost to health services and communities, and compare burn treatment to minimum clinical guidelines to identify gaps; (3) identify barriers to healthcare for Aboriginal and Torres Strait Islander children who sustain serious burns, from the perspective of the patient, their families

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and their health care providers, and document the extent to which these barriers contribute poor health outcomes; (4) inform the development of clear and practical clinical guidelines and a strategy for their use in health services and community settings.

METHODS AND ANALYSIS

Eligible population and recruitment

All children under 16 years presenting or referred for treatment for burns to participating tertiary burn units in the Australian states of New South Wales (NSW), Queensland, South Australia (SA) and the Northern Territory (NT) will be eligible for participation. All parents/carers will be asked whether the child is Indigenous using the Standard Indigenous Question[17] at time of presentation at the burn unit as part of routine admission questions. Once survival of the child is assured, patient care teams will be consulted about the optimal time for recruitment into the study. Eligible families will be approached and given written and verbal information about the study during the first visit to the burn unit, prior to patient discharge. If the patient care team feels it appropriate, on this visit, eligible families will be asked to participate and complete a baseline interview. If recruitment is not possible on the first visit, families will be approached on the subsequent visit.

Consent will be obtained from parent or guardian for participation in the study. Children will also participate in the consent process if they are aged 12 years and above and the parent or guardian deems them able to participate in the consent process. Consent will also be requested to contact the usual medical provider at participants' places of residence or health practitioners who are involved in burn treatment subsequently and access burn-related medical records. Participants will also be asked to consent to primary care practitioners being involved in data collection, for example, in the case of those living in remote settings whereby local healthcare providers may be asked to administer follow-up questionnaires. Separate consent to access Medicare Benefit Scheme (MBS) and Pharmaceutical Benefit Scheme (PBS) records (allowing details of Government subsidised healthcare and pharmaceutical services utilised) will also be obtained.

Data will be collected using both quantitative and qualitative approaches. Data collection will include (1) participant interviews, (2) capture of clinical data from medical records and (3) linkage to MBS/PBS records. Additionally, to identify barriers and enablers to healthcare for Aboriginal and Torres Strait Islander children who sustain serious burns, from the perspective of the patient, their families and their healthcare providers, qualitative research will be conducted in a range of settings. Documentation of patient journeys, systems mapping of services and evaluation of health professionals' enactment of care will also be conducted. The information from all sources will be brought together with key stakeholders in policy roundtable sessions to inform discussion around development of appropriate models of care.

Baseline interview

Information collected at the baseline interview will include basic sociodemographic data (age, place of residence, measures of family structure, income and education), the burns first aid treatment (type, time from injury and duration), the timing of treatment, mode and timing of transportation to hospital, and preinjury quality of life. Tools used to measure sociodemographic characteristics, family disruption and family structure will be adapted from previous surveys including the NSW Population Health Survey[18] and the Western Australian Aboriginal Child Health Survey, which developed and tested measures specifically for Aboriginal children and their families;[19] clinical data will be extracted from patient medical records and preinjury quality of life measured using the Pediatric Quality of Life Inventory (PedsQL).[20] To assess parental trauma (as the trauma experienced by the parent may influence care sought for the child), parents will also be asked to complete the Kessler 5 scale.[21] Brief questions will also be asked about family disruption and travel related to treatment needs. Recruitment and baseline interviews will be conducted by trained Aboriginal or Torres Strait Islander research staff or by research staff with significant experience working with Aboriginal or Torres Strait Islander people.

Follow-up interviews

Follow-up interviews will be conducted at 3, 6, 12 and 24 months postinjury; the multiple measures are needed to determine recovery patterns and the more permanent consequences of injury.[22] The interview will be conducted with the parents/carers. Data will be collected on care received (and out of pocket costs) since the last interview, health-related quality of life using the PedsQL,[20] pain, itch and activity limitations of the child as per baseline interviews, and return to school. If children are aged 5 years and over, they will also be asked to complete health-related quality of life measures, and measures of pain and itch. At annual interviews (12 and 24 months), parents/carers will also be asked to complete measures of psychological distress for themselves (Kessler 5), health-related quality of life measures for the child and brief questions on disruptions to family or employment due to treatment or caring needs. Details of outcomes measured are presented in table 1.

Clinical data

The study research assistant at each site will extract information from clinical notes at regular intervals, including at baseline. This will include external cause and context of injury, operative procedures, outpatient visits, including number of visits to each service (eg, occupational therapist, psychologist, Aboriginal health worker, access to interpreter services), and scar management. In order

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Table 1 Outcomes collected at various time points

Measure	Baseline	3 months	6 months	12, 24 months
Interview	Demographics	Treatment	Treatment	Treatment
	HRQOL*	HRQOL*	HRQOL*	HRQOL*
	Injury	Pain	Pain	Pain
	Initial treatment	Itch	Itch	Itch
	Kessler 5	Family Disruption	Family Disruption	Family disruption
	Family Demographics	Kessler 5	Kessler 5	Kessler 5
	Family function	POSAS†	POSAS†	POSAS†
Clinical data	Hospital Medical	POSAS†	POSAS†	POSAS†
	Records Data‡	Hospital Medical Records Data‡	Hospital Medical Records Data‡	Hospital Medical Record Data‡

*HRQOL: Health-related quality of life collected via PedsQL.[20]
†POSAS: Patient and Observer Scar Assessment Scale.[23]
‡Hospital Medical Record Data. Injury: context, prehospital care, including transfers and specific events. Patient's social history, medical history, details of multidisciplinary care, dressings and intensive care admissions. Procedures for theatre and additional burn assessment notes.

to collect data on treatment, the research assistant, when appropriate, will have access to attend the weekly case conference meeting for each unit. Clinical information collected at baseline: date of burn, %TBSA, depth of burn, location of burn (eg, hand, feet, face, genitals), ventilator days, surgical care (how much, timing, type), admission/length of stay to intensive care units, overall length of stay, complications (renal impairment, weight loss), where the patient is discharged to, type of care (use of splints, compression garments), assessment of activity limitation (from clinical notes) and measures of scarring using the Patient and Observer Scar Assessment Scale (POSAS).[23] Clinical information will be collected at each follow-up visit or hospitalisation at the burn unit; if the patient follow-up interviews reveal care is received at other sites (eg, other hospitals), medical records will be accessed at those sites. Once the participant has agreed to participate in the study, a letter will be sent to the general practitioner and any allied health practitioners expected to be involved in follow-up care requesting cooperation in collection of study data including potential administration of questionnaires if required. At 6, 12 and 24 months from injury, a standard form (followed up by phone calls) will be sent to the participant's medical practitioner locally to request data on local clinical care, including services delivered by physiotherapists, nurses, counsellors or other allied health practitioners, and measures of patient health status if known.

We will also document the existing models of local and regional burn services in each study site. This will include mapping service provision at each site, documenting the model of care, from presentation to rehabilitation and follow-up care in the community. We will identify both structure—the organisation, communication, referral processes, rehabilitation and community outpatient care in place; and processes—the existence and use of structured care plans, clinical pathways, assessment protocols, rehabilitation prescriptions, and postdischarge management pathways in each site.

Medicare linkage

To access data on use of healthcare utilisation, participants will be asked for separate consent to link to MBS and PBS records. Items collected will include item numbers/description, including hospital and community items, type of specialty of provider, postcode of participant, postcode of provider and fee paid, including payments on Medicare-extended care plans which allow access to physiotherapy treatment and other allied health services. As, particularly in remote areas, a proportion of patients will be mobile, their Medicare records will allow ascertainment of location and frequency of treatment if contact with carers or participants is lost. Linkage will occur at the end of 24-month follow-up. Medicare is used to pay for most patient visits to medical practitioners in Aboriginal Medical Service settings, so this is a feasible way to track healthcare use, although it will not collect data on wound management, attendances at private practitioners. The proportion of visits missed will be checked by cross-referencing against patient interview data.

Qualitative research

In order to ascertain the impact of burn care and outcomes on family life, and understand needs of patients, and barriers to healthcare, including from the perspective of providers and policymakers, qualitative research is required. Qualitative research will be performed using Aboriginal ontology as a holistic framework that is based on interconnectedness, person-centred care and Aboriginal ways of knowing.[24] Where required, the Aboriginal interpreter service will be employed for any families without English as a first language. Interviews will be audio recorded, transcribed in full and verified with participants to ensure trustworthiness of data.[25]

Patient and family perspectives

We will conduct semistructured interviews with individuals or small family groups, and a sample of families will be interviewed in each state. This will elicit feelings

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and reflections of the complexity of care experienced[26] including the barriers to care and treatment, including components of treatment prescribed for use in community settings, such as use of compression garments. Families and their primary care providers at each site will be recruited by the research nurse and interviewed in the community until saturation of themes. Both urban and rural participants will be interviewed to identify issues relevant to each setting. Where qualitative interviews can generate rich contextual data,[27] there is also a risk that data become a research commodity[28] dissociated from cultural meanings.[29] Particular care will be taken during interviews to ensure that the data remain connected to the larger moral community[28] and are explicitly co-constructed between researcher and participants.[30] Data will be transcribed and analysed thematically using content analysis. Detailed information on the participant's personal experience and factors influencing injury outcomes will be explored; results will be triangulated with questionnaire data to inform better understanding of factors impacting on outcomes.

Clinical and stakeholder perspectives

To better understand the barriers and enables at an institutional level, data will be collected following a three-tiered process to map patient journey, map health services and evaluate attitudes to care. In order to map patient journey, this study will utilise the Managing Two Worlds Together, Patient Journey Mapping Tool.[31] Case study methodology will be used to map the actual patient journey of three Aboriginal or Torres Strait Islander children as they access health services following burn injury. The participants will be drawn from the overarching study. A narrative analytical approach will be used, and semistructured interviews with patients and their carers will be conducted asking questions about their experiences and the barriers and enablers to good care. The story will be written using Emden's core story creation narrative analysis and will use the relevant mapping tools as described in the Journey Mapping Tool.[31] In order to map and describe the provision of care in health services enacted by health professionals, lead burn clinicians at each of the leading burn units in Australia will be consulted. During on-site consultation and observations, the lead burn clinicians will be asked in semistructured interviews to provide a description of typical patient burn care and pathways followed on presentation of a client with a burn injury. Health professionals and administrators involved in care along the patient pathways and state policy makers will also be consulted. Interviews will have a particular focus on system level approaches to care. The mapping will include both structure—the organisation, communication, referral processes, rehabilitation and community outpatient care in place; and processes—the existence and use of structured care plans, clinical pathways, assessment protocols, rehabilitation prescriptions and postdischarge management pathways in each site. To identify attitudes to care at an institutional level, including health professionals and policymakers involved in the management of burn injury, we will conduct a broad stakeholder consultation involving qualitative evaluation of knowledge, attitudes, practices and perceived needs of patients. The consultation will use in-depth semistructured interviews and will focus on management of burns, and perceived barriers to treatment, with a particular focus on system level approaches to establish a clear representation of how clinical guidelines are enacted.

All qualitative data will be analysed thematically, contextualised and triangulated to enable a better understanding of burn care for Aboriginal and Torres Strait Islander children.

Sample size and analysis

Retrieval of data from each site suggests that there are approximately 120 children presenting to or being referred to the burn units participating in this study each year, with between 10 and 20 each year for NT and SA units, and 40 and 50 for NSW and Queensland. However, given possible undercounting this may be as large as 150 or greater. Participants will be recruited until 225 participants have been recruited (over approximately 18–20 months, expected conservative participation rate of at least 60%).[32] We anticipate collecting follow-up interview data for 2 years on approximately 70% of participants which will allow complete data on 130 children.[32]

We will document care received and describe patterns and characteristics of care by state, by place of residence, injury severity, and describe the proportions of children whose care meets standard clinical practice guidelines for medical management for paediatric burns.[5] We will estimate the incidence of burn injuries in Aboriginal and Torres Strait Islander children presenting to burn units in each participating state, by extracting population counts for each state including age and gender distributions for Aboriginal and Torres Strait Islander people from the Australian Bureau of Statistics (ABS) Census data.

We will investigate the key predictors of health-related quality of life scores, and burn-related functional outcomes, including activity limitations, pain and return to school using random or mixed effects regression models. Measures to be assessed include age, gender, family function, type/amount of treatment received (including scar management/compression garments/splints), type of patient (inpatient vs outpatient), place of residence (urban/rural) and psychological distress of parent and child. Although there is no literature describing predictors of PedsQL in children with burns, the following variables have been found to have an impact on the SF-36 score in paediatric patients with burns: age at injury, gender, functional family, early reintegration and consistent clinic visits; PedsQL scores have also been described in Australian children sustaining trauma, including burns.[33] With 130 patients, four postbaseline measures at 3, 6, 12 and 24 months for each patient, correlation between two scores from the same participant is

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assumed to be 50%, and assuming an exchangeable correlation matrix structure, we will have 80% power to determine a minimum absolute difference (increase or decrease) of +/− 0.3 in global scores for each of the factors examined. The calculations are based on optitxs.r macro using R software V.3.1.3.

Linkage to MBS and PBS data will also provide important data on healthcare utilisation, particularly important where we may have significant loss to follow-up. We will examine healthcare utilisation by severity of burn, remoteness of place of residence and sociodemographic factors such as family structure, and age of child.

The cost analysis will adopt a health sector perspective and include costs borne by government, other agencies and families/carers. Costs will be assessed using a micro costing approach with all costs identified and valued for individual patients. Information on the use of health services will be collected from multiple sources including follow-up interviews with families/carers, clinical data and Medicare and PBS records. The cost of treating children with burn injuries will be calculated based on their resource use and the corresponding costs. These data will then be analysed using two approaches. First, a prevalence-based approach will be used to identify (1) the overall cost of treating burn injuries for the cohort of Aboriginal children and (2) costs disaggregated by cost component, subgroup and source of funds. Second, an individual-based approach will be adopted in which we will investigate associations between the mean individual cost and various factors including patient characteristics, healthcare utilisation and health outcomes using multiple linear regression techniques.

Governance

The study is managed by a project management committee, comprising the investigators and associate investigators, and research staff. This group has oversight of the study protocol, implementation and production of key outputs. An advisory group ensures community input into the study, and provides high level oversight of methods and relevance. This committee will ensure the processes used are cognisant of Indigenous understandings of health and well-being, that data analysis is based in an appropriate context and that meaningful dissemination and knowledge transfer activities occur. This will be chaired by an Indigenous member of the investigative team, and will include healthcare providers from primary care, including from Aboriginal Community Controlled Health Organisations as well as tertiary care providers and Aboriginal liaison units from the participating hospitals as well as the investigators and other state burn representatives. Community members will also be invited from each state.

ETHICS AND DISSEMINATION

Study results will be published in peer-reviewed journals presented at conferences and seminars; a study newsletter will be distributed regularly to participating families, community groups and Aboriginal peak bodies, and results will be disseminated via meetings, lay reports and via the study website. Policymakers, clinicians involved in treatment, pain management and rehabilitation in burn care (tertiary and community based), representatives of ACCHS and researchers will be invited to participate in policy roundtable discussions in years 1, 3 and 4 to plan the study, review findings, discuss implications for policy development, and consider avenues and opportunities for implementation.

IMPLICATIONS

This study will investigate the previously understudied area of burns in Aboriginal and Torres Strait Islander children and identify the treatment received and its cost to health services and communities, and compare burn treatment to minimum clinical guidelines to identify gaps. Understanding what compromises cost-effective, clinically and culturally appropriate treatment for these injuries will substantially improve the evidence base and contribute to better care. We will quantify comprehensively the evidence practice gap on receipt of appropriate care and examine the impact on function; conduct a detailed barrier analysis of the underlying reasons for these gaps at the individual/ family, community, healthcare provider and health service levels; and establish a 'blueprint' for reform to overcome these barriers through engagement with communities, decision makers and other key stakeholders, guiding future intervention research. This study, with a combination of detailed interview, clinical and contextually rich qualitative data, offers a unique opportunity to generate, using a best practice, collaborative approach, important evidence to inform development of improved models of care for what is an over-represented and vulnerable population. Exploring the complexities of burn care for Aboriginal Australians will serve as a model for engaging health system reform that meets the needs of not only other disadvantaged groups in Australia, including people of low-income and of non-English speaking background, but also the broader population, as well as having important implications for burn care internationally.

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Competing interests None declared.

Ethics approval The study has been approved by ethics committees in each state, including the relevant Aboriginal health ethics bodies. These include the Human Research Ethics Committee of Northern Territory Department of Health and Menzies School of Health Research (EC00153); Central Australian Human Research Ethics Committee (EC00155); Aboriginal Health Research Ethics Committee (EC00185) (SA); Women's & Children's Health Network Human Research Ethics Committee (EC00197) (SA); Aboriginal Health & Medical Research Council of NSW Ethics Committee (EC00342); Sydney Children's Hospitals Network Human Research Ethics Committee (EC00130); The University of Queensland Medical Research Ethics Committee (EC00179); Children's Health Services Human Research Ethics Committee (EC00175) (QLD); Townsville Hospital and Health Service Human Research Ethics Committee (EC00183) (QLD); Department of Health Human Research Ethics Committee (EC00106) (National) and the Department of Human Services (for access to Medicare and Pharmaceutical benefits data).

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Indigenous research methodology – weaving a research interface

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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.

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