

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

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January 2021

*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

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Certificate of Original Authorship

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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.

This research is supported by the Australian Government Research Training Program.

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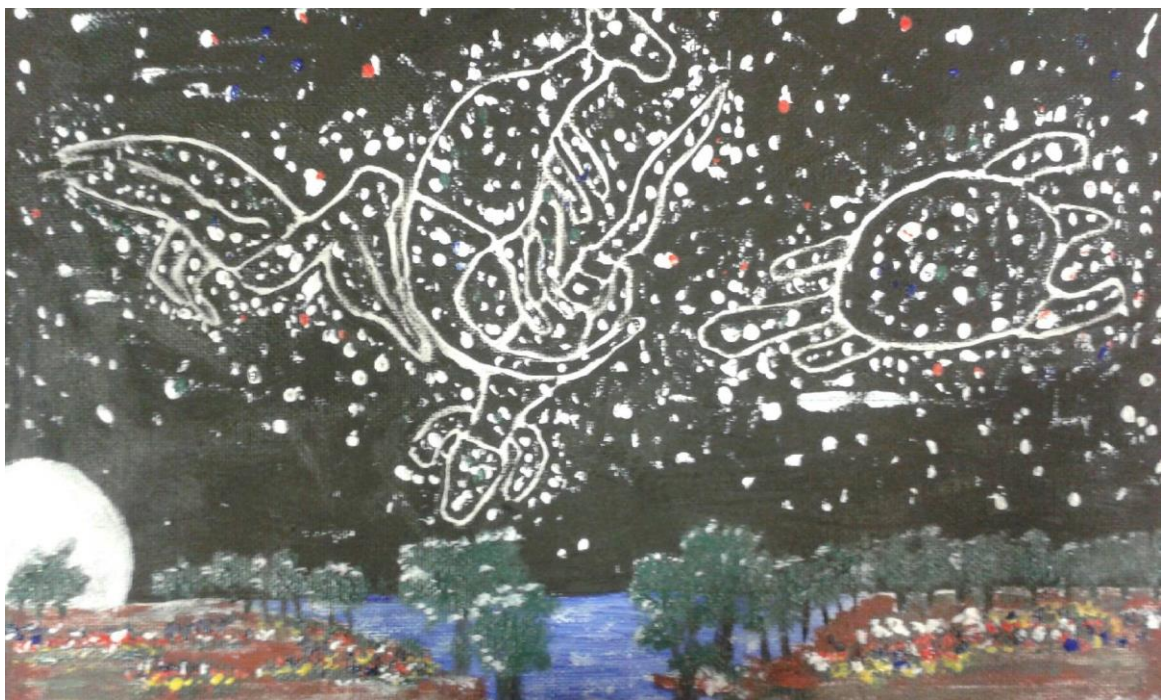
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Date: 12th January 2021

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.

I am incredibly appreciative of my supervisor Professor Rebecca Ivers who kept my travel time under control and with her guidance could complete this thesis on time, and I am eternally grateful for that. When things seemed too hard or even impossible, she encouraged me to keep going. Thank you, Professor Elizabeth Sullivan, for your encouragement, educated guidance and supervision. To my co-supervisor Tamara Mackean, who understood my need for cultural integrity and for teaching me what it means to work within a culturally appropriate methodological framework. When I think of how much I have learnt from Tamara many important lessons stay with me: but one stands out, and that was “*never forget where we come from*”. The number of times I struggled to bring the two worlds of Western academia and Indigenous knowledges together and almost gave up, she would patiently explain, “*The voice of our people matters the most*”. It is for this reason that I could go on to complete my thesis. Kate Hunter’s patience and understanding of where I was coming from at the different times in my writing gave me the strength to continue, her infectious smile while guiding me through my study is something I will always remember. So much of what I learnt along the way came from the “The Coolamon Study”, which has been an emotional roller coaster. The study has given a voice to First Nations people of Australia and has given hope for change in our health systems. Kate Hunter, I thank you for allowing me to be a part of something unique.

To all my co-researchers past and present who supported me and travelled with me to communities and families to yarn with them I thank you so much for our cultural journey together, Melissa, Tanya, Karen, Sarah, Loyla, Brea, Courtney, Samara and Philadelphia.

My cultural integrity stayed intact thanks to so many wonderful Aboriginal academic leaders, friends and family. Your guidance, strength and encouragement to hold steadfast to my knowing, being and doing was invaluable to my sanity in working within two worlds. Kathleen Clapham, Bobby Porykali, Elizabeth Bourke, Aunty Jean

Anne-Marie Eades and so many more, I thank you. Keziah Bennett-Brook you have become a beacon of light during my last year of this journey and my last day as a student was spent together making sure every step was taken to ensure my submission was successful, thank you my strong little Tidda.

And of course, a big thank you to Caroline Lukaszuk for your continued support, your friendship and always being there to look over my work even though you were busy doing your own PhD, I will always be in your debt and from the moment we started working together I knew we would be lifelong friends. To my dearest friends who always encouraged me to keep trying and always told me how proud they were of me: Cheryl Whatman and so many others that it is impossible to name them all.

The most important people I need to thank are my wonderful family, my children who have complained that I never spend time with them but still encouraged me when I believed I was never going to finish. Rebecca, Natasha, Bianca, Samara and Tiana I dedicate this thesis to you. Always believe in yourself and never give up, you all come from a line of strong women. To all my grandchildren and my great grandchild, I promise to be a strong culture leader and loving grandmother (Marnie) to you all.

To my mum, Gwendoline Helen Smith, who I dearly miss, you set my course to start my journey in my PhD as a child. You always knew one day I would be Dr J Coombes. I am so grateful to have had you as my mum, for your support and your belief in me as I grew. You were and still are the rock I needed to fulfil my dreams.

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)	
<i>Title</i>	Walking together to create harmony in research.
<i>Authors</i>	Coombes J , Ryder C.
<i>Journal</i>	<i>Qualitative Research in Organizations and Management</i>
<i>Status of publication</i>	Published – 2019; epub 30 July, doi: 10.1108/QROM-07-2018-1657
<i>Unique contribution to knowledge</i>	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)	
<i>Title</i>	Factors that impact access to ongoing health care for First Nation children with a chronic condition.
<i>Authors</i>	Coombes J , Hunter K, Mackean T, Holland AJ, Sullivan E, Ivers R.
<i>Journal</i>	<i>BMC Health Services Research</i>
<i>Status of publication</i>	Published - 2018;18(1):448, doi: 10.1186/s12913-018-3263-y
<i>Unique contribution to knowledge</i>	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)	
<i>Title</i>	The Journey of Aftercare for Australia's First Nations Families Whose Child Had Sustained a Burn Injury
<i>Authors</i>	Coombes J , Hunter K, Mackean T, Sullivan E, Ivers R.
<i>Journal</i>	<i>BMC Health Services Research</i>
<i>Status of publication</i>	Published 2020 Dec;20(1):1-1 doi: BHSR-D-20-00587R3 .
<i>Unique contribution to knowledge</i>	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)	
<i>Title</i>	"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
<i>Authors</i>	Coombes J , Hunter K, Mackean T, Sullivan E, Ivers R.
<i>Journal</i>	Public Health Research & Practice
<i>Status of publication</i>	Submitted, 13 October 2020
<i>Unique contribution to knowledge</i>	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.
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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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