A DISJUNCTURE OF WORLD VIEWS:
manifestation in burns care for Aboriginal and Torres Strait Islander children in Australia

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CONTENTS

THESIS SUMMARY

This collaborative qualitative research study investigated burns care for Aboriginal and Torres Strait Islander children in Australia. Set within Australia's health system, it explored burns care from the point of view of those working in burns teams. This involved respectful approaches addressing issues related to colonisation, imbalances of power relations and constructs of equality and equity.

Aboriginal and Torres Strait Islander children suffer burns injury at disproportionally higher rates than non-Indigenous children (AIHW 2011b). This research arose because it was unclear what guides burns care for these children; how burns care is delivered and structured, and if it meets the needs of this population. The research forms part of a larger National Health and Medical Research Council (NHMRC) funded project investigating burns injury in Aboriginal and Torres Strait Islander children. The larger study has various foci including quality, safety, cost and impact of care, and health outcomes for Aboriginal and Torres Strait Islander children. With a keen interest and strong nursing history in Aboriginal health, I joined the NHMRC project as a research assistant and PhD student.

The setting for the research was tertiary burns units located across five jurisdictions in Australia. I sought to explore how burns care is delivered, with a focus on care for Aboriginal and Torres Strait Islander children and families. Throughout the project the focus broadened to include the health system. This provided an opportunity to explore the wider context in which burns care is delivered.

A strong commitment to Aboriginal and Torres Strait Islander health research ethics (NHMRC 2003) provided the foundation of this research. I worked closely and meaningfully with Aboriginal and Torres Strait Islander co-researchers across the entirety of the project. I engaged in reflexive research (Wilson 2014) and assessed myself and my position, including identifying my Whiteness and the impact of this on the research. These learnings informed this research and examples of my engagement in reflexivity are evident throughout the entirety of this thesis.

This research identified that a mostly Western biomedical paradigm informs burns care for Aboriginal and Torres Strait Islander children and families in Australia. This was closely linked to burns team members' limited understanding of the need to provide different care based on needs. For Aboriginal and Torres Strait Islander children and families, this means the delivery of best quality burns care is not fully realised.

This research used interface research methodology and was guided by the theory of decolonisation. The findings reinforce the need for quality and cultural safety in the guidance and

application of burns care in Australia. While there are opportunities for improvement, tangible action at all levels of the healthcare system are necessary to ensure beneficial and sustainable change.

DECLARATION

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

STATEMENT OF THE CONTRIBUTION OF OTHERS

This thesis has been made possible through the support of many people, including those as follows:

Supervisors

- Associate Professor Julian Grant, College of Nursing & Health Sciences, Flinders University
- Professor Rebecca Q Ivers, Public Health & Community Medicine, University of New South Wales
- Dr Tamara Mackean, Southgate Institute for Health, Society and Equity, Flinders University
- Dr Kate Hunter, The George Institute for Global Health, University of New South Wales

Other significant contributors

- Associate Professor Warwick J Teague, The Royal Children's Hospital, University of Melbourne
- Mrs Ngara Keeler, Aboriginal Health Council of South Australia

Co-authors

- Professor Andrew Holland, Sydney Medical School, The University of Sydney
- Professor Kathleen Clapham, University of Wollongong
- Mr Kurt Towers, Northern Adelaide Local Health Network
- Professor Tom Potokar, University of Swansea, United Kingdom
- Associate Professor Dale W Edgar, The University of Notre Dame
- Dr Janet Kelly, South Australian Health and Medical Research Institute
- Dr Bronwyn Griffin, Queensland University of Technology
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Cultural Mentors

- Supervisor, Dr Tamara Mackean, Southgate Institute for Health, Society and Equity, Flinders University
- Fellow project PhD students: Julianne Coombes (the George Institute for Global Health), Courtney Ryder (The George Institute for Global Health), Hayley Williams (Centre for Children's Burns and Trauma Research, University of Queensland)
- AHCSA colleagues (past and present): in particular Ngara Keeler, Amanda Mitchell and Stan Butler
- Aboriginal and Torres Strait Islander Advisory Group for the overall National Health and Medical Research Centre burns study

- Co-authors: Professor Kathleen Clapham, Mr Kurt Towers, Associate Professor Dale W Edgar

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Collaboration

- A project of this nature requires highly collaborative and respectful approaches to knowledge sharing. I consulted with many Aboriginal and non-Aboriginal health professionals, researchers and healthcare professionals. In particular I would like to acknowledge the guidance of my Aboriginal supervisor Dr Tamara Mackean in facilitating many of the collaborative processes.

Editing

- Professional editing of this thesis has been carried out by an editor engaged through the company *You Can't Handle the Proof*.

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Thank you also to all of the co-researchers in the larger project, for bringing their time, energy and knowledge to our collaboration. Special thanks to those who became involved in co-writing papers and articles shared in this thesis. Thanks also to my fellow PhD candidates in this large project who shared the study journey with me. A special thank you to Ngara Keeler for your important contribution and cultural mentorship.

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Thank you to family, friends and colleagues; your encouragement has been totally appreciated. Thank you to my employer overall, the Aboriginal Health Council of South Australia for your commitment in supporting me with this important project. Thank you to my sister, Emily Fraser for always believing in me. Finally, to Mark, Stella and Ewan. Thank you for always supporting me and my commitment to this research and my work with others towards improving healthcare for and with Aboriginal and Torres Strait Islander children and families in Australia.

LIST OF PUBLICATIONS

Throughout the PhD research, manuscripts were prepared and submitted to various journals for consideration for publication. The list below provides details at the time of submitting this thesis for examination. These publications and submitted manuscripts are presented throughout the thesis where appropriate. Two publications are included as Appendices. These publications, while relevant to this PhD, were contributed to throughout the process of the PhD; however they are included as appendices as I am not the primary author.

Published

Fraser, S, Mackean, T, Grant, J, Hunter, K, Towers, K and Ivers, RQ (2017) Use of telehealth for health care of Indigenous peoples with chronic conditions: a systematic review*. Rural and Remote Health* 2017, vol. 17, issue 3, https://doi.org/10.22605/RRH4205.

Fraser, S, Grant, J Mackean, T, Hunter, K, Holland, AJA, Clapham, K, Teague, WJ and Ivers, RQ (2018) Burns injury models of care: a review of quality and cultural safety for care of Indigenous children. *Burns*, vol. 44, issue 3, pages 665-667, https://doi.org/10.1016/j.burns.2017.10.013.

Fraser, S, Grant, J, Mackean, T, Hunter, K, Keeler, N, Clapham, K, Teague, WJ, Potokar, T and Ivers, RQ, Submitted December 2018, What informs care? Descriptions by multidisciplinary teams about burns care for Aboriginal and Torres Strait Islander children, *Burns,* https://doi.org/10.1016/j.burns.2019.07.039.

Submitted ***(under review)***

Fraser, S, Mackean, T, Grant, J, Hunter, K, Keeler, N, Teague, WJ, Clapham, K, Towers, K, Edgar, DW and Ivers, RQ, Submitted February 2019, Considering difference: clinician reports of providing equal and equitable burns care for Aboriginal and Torres Strait Islander children and families, *International Journal for Equity in Health.*

Fraser, S, Mackean, T, Grant, J, Hunter, K, Kelly, J, Holland, AJA, Teague, W, Clapham, K, Griffin, B, Darton, A and Ivers, R, Submitted March 2019, Formative evaluation of a patient journey mapping tool to investigate quality and cultural safety in burns care for Aboriginal and Torres Strait Islander children and families, *BMJ Quality and Safety*.

Appendices ***(published)***

Ivers, RQ, Hunter, K, Clapham, K, Coombes, J, Fraser, S, Lo, S, et al (2015), Understanding burn injuries in Aboriginal and Torres Strait Islander children: protocol for a prospective cohort study, *BMJ*, vol. 5, issue. 10, https://doi:10.1136/bmjopen-2015-009826.

Jagnoor, J, Lukaszyk, C, Fraser, S, Chamania, S, Harvey, L, Potokar, T, and Ivers, RQ (2017), Rehabilitation practices for burn survivors in low and middle income countries: a literature review, *Burns*, vol. 44, issue. 5, https://doi.org/10.1016/j.burns.2017.10.007.

LIST OF PRESENTATIONS

Throughout the PhD journey, abstracts were prepared and submitted to various conferences for consideration for presentation. The list below provides details of accepted and presented papers at the time of submitting this thesis for examination.

2017 Annual Scientific Meeting of the Australian & New Zealand Burn Association, Adelaide Oval, 24th – 27th October 2017, Adelaide, Australia.

Title: Burns injury models of care: a review of quality and cultural safety for care of Indigenous children

Authors: Sarah Fraser (presenting), Julian Grant, Tamara Mackean, Kate Hunter, Andrew Holland, Kathleen Clapham, Warwick Teague and Rebecca Ivers

13th Australasian Injury Prevention and Safety Promotion Conference 13th – 15th November 2017, Ballarat, Victoria, Australia.

Title 1: Burns care for Aboriginal and Torres Strait Islander children: guidance and approach to care

Authors: Sarah Fraser, Tamara Mackean, Julian Grant, Kate Hunter, Warwick Teague, Tom Potokar and Rebecca Ivers

Title 2: Burns injury models of care: a review of quality and cultural safety for care of Indigenous children

Authors: Sarah Fraser (presenting), Julian Grant, Tamara Mackean, Kate Hunter, Andrew Holland, Kathleen Clapham, Warwick Teague and Rebecca Ivers

2018 Annual Scientific Meeting of the Australian & New Zealand Burn Association, 16th – 19th October 2018, Brisbane, Queensland, Australia.

Title: What informs care? Descriptions by multidisciplinary teams about burns care for Aboriginal and Torres Strait Islander children

Authors: Sarah Fraser (presenting), Julian Grant, Tamara Mackean, Kate Hunter, Ngara Keeler, Kathleen Clapham, Warwick Teague, Tom Potokar and Rebecca Ivers

19th Congress of the International Society for Burn Injuries, 30th November – 4th December 2018, Gurugram, Delhi, India.

Title 1: Burns injury models of care: a review of quality and cultural safety for care of Indigenous children

Authors: Sarah Fraser (presenting), Julian Grant, Tamara Mackean, Kate Hunter, Andrew Holland, Kathleen Clapham, Warwick Teague and Rebecca Ivers

Title 2: What informs care? Descriptions by multidisciplinary teams about burns care for Aboriginal and Torres Strait Islander children

Authors: Sarah Fraser (presenting), Julian Grant, Tamara Mackean, Kate Hunter, Ngara Keeler, Kathleen Clapham, Warwick Teague, Tom Potokar and Rebecca Ivers

The Lowitja Institute International Indigenous Health and Wellbeing Conference, 18-20 June 2019, Darwin, Northern Territory.

Title 1: Considering difference: clinician reports of providing equal and equitable burns care for Aboriginal and Torres Strait Islander children and families

Authors: Sarah Fraser (presenting), Tamara Mackean (presenting), Julian Grant, Kate Hunter, Ngara Keeler, Warwick J Teague, Kathleen Clapham, Kurt Towers, Dale Edgar, Rebecca Ivers

AWARDS

Throughout the PhD journey I was the recipient of the following awards and grants:

2017 College of Nursing & Health Sciences RHD Student Publication Award - Flinders University
Fraser, S, Mackean, T, Grant, J, Hunter, K, Towers, K and Ivers, RQ (2017) Use of telehealth for health care of Indigenous peoples with chronic conditions: a systematic review*. Rural and Remote Health* 2017, vol. 17, issue 3, https://doi.org/10.22605/RRH4205.

Research Student Conference Travel Grant (April 2018) - Flinders University
19th Congress of the International Society for Burn Injuries, Nov 30 - Dec 04, 2018, Gurugram, Delhi.

'Best Burns Care Presentation' (November 2018) - 42nd Annual Scientific Meeting of the Australia and New Zealand Burn Association
Fraser, S, Grant, J, Mackean, T, Hunter, K, Keeler, N, Clapham, K, Teague, WJ, Potokar, T and Ivers, RQ (2018) What informs care? Descriptions by multidisciplinary teams about burns care for Aboriginal and Torres Strait Islander children.

2018 College of Nursing & Health Sciences RHD Student Publication Award - Flinders University
Fraser, S, Grant, J Mackean, T, Hunter, K, Holland, AJA, Clapham, K, Teague, WJ and Ivers, RQ (2018) Burns injury models of care: a review of quality and cultural safety for care of Indigenous children. *Burns*, vol. 44, issue 3, pages 665-667, https://doi.org/10.1016/j.burns.2017.10.013.

2018 Best Higher Degree by Research Student Publication - Flinders University
Fraser, S, Grant, J Mackean, T, Hunter, K, Holland, AJA, Clapham, K, Teague, WJ and Ivers, RQ (2018) Burns injury models of care: a review of quality and cultural safety for care of Indigenous children. *Burns*, vol. 44, issue 3, pages 665-667, https://doi.org/10.1016/j.burns.2017.10.013.

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TERMINOLOGY

Aboriginal and Torres Strait Islander

An official title used to describe Australia's first peoples (Taylor & Guerin 2014, pp. 4-5). I use this term throughout this thesis when referring to Australian Aboriginal and Torres Strait Islander peoples.

Colonisation

In this thesis, colonisation refers to the past and present actions of a dominant group establishing control over Indigenous peoples in different regions of the world. In Australia, this relates specifically to the past and present actions by the settler society and subsequent Western government, systems and peoples that have (usually negatively) impacted on Aboriginal and Torres Strait Islander peoples, especially regarding heath (Paradies 2016).

First Nations

This term refers to the first inhabitants of a land and whose ancestors lived in before the arrival of Europeans (Assembly of First Nations).

Indigenous

Originating in a particular region or Country (WHO 2007). A term often used to describe Aboriginal and Torres Strait Islander people in government documents; but not a term used by many of my Aboriginal co-researchers. This term was used in this research and throughout the thesis when talking about Indigenous people from different countries around the world and also to describe white people: non-Indigenous.

Western biomedical

A term used to describe the dominant grounding and ways of Australia's healthcare system (Best & Fredericks 2018, p. 56).

White

A term many Aboriginal people use to name non-Indigenous people in relation to themselves (Taylor & Guerin 2014, p. 65, Wilson, Kelly, Magarey et al. 2016, p. 8). Some non-Indigenous people (including myself) adopt this term to describe themselves in relation to Aboriginal people, particularly when discussing issues related to colonisation (Wilson, Magarey, Jones et al. 2015, p. 3). The term 'white' does not refer to skin colour, rather it refers to a person's non-Indigenous identity. This is because many Indigenous people have fair, or white skin colour.

ACRONYMS

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Service
AHCSA	Aboriginal Health Council of SA
AHP	Aboriginal Health Practitioner
AHW	Aboriginal Health Worker
ALO	Aboriginal Liaison Officer
A/ILO	Aboriginal/Indigenous Liaison Officer
ILO	Indigenous Liaison Officer
MoC	Model of Care
NHMRC	National Health and Medical Research Council
WHO	World Health Organization
UN	United Nations

THESIS STRUCTURE

The aim of this thesis is to present an investigation of how burns care in Australia is delivered in and from tertiary burns units and what informs the burns care multidisciplinary burns teams provide. The research also aimed to develop and pilot a patient journey mapping tool to facilitate assessment and evaluation of quality in the burns care journeys' of Aboriginal and Torres Strait Islander children and families.

The thesis is separated into four main sections:

Section A

In this section I lay the theoretical grounding for the overall research setting and introduce the health outcome inequities experienced by Aboriginal and Torres Strait Islander children. In chapter one I present how I came to be part of this research project and introduce reflexivity as a central methodology for my engagement with this project. By including this information first I am acknowledging my influence and situating myself in this important research project. This is followed by chapter two in which I provide a detailed description and justification of the theoretical framework engaged for the research. The structure of this thesis reflects the importance of placing oneself as integral to the overall research process. As such, these first two chapters of the thesis are an exploration of my standpoint (as a non-Indigenous researcher) and an introduction into different ways of knowing, being and doing.

Section B

In this section I introduce burns injury epidemiology and what is known about burns care, especially as it relates to Aboriginal and Torres Strait Islander children and families. Following the presentation of this literature is the inclusion of two published systematic reviews. The first is an investigation of the literature concerning telehealth as a modality for the provision of care for chronic conditions, including burns rehabilitation. The second is investigating the quality and cultural safety in burns injury models of care.

Section C

In this section I present a combination of methods, findings and discussion. <u>Two</u> distinct methods were engaged. The <u>first</u> was interviews with healthcare professionals and administrative staff employed in burns teams in tertiary health services across Australia. Following a description of these methods, two outcomes papers submitted for publication in *Burns* and *International Journal for Equity in Health* are presented. These manuscripts present findings on what informs burns care and the considerations of different care for Aboriginal and Torres Strait Islander children and families. The second method engaged concerns the development of a patient journey mapping tool for assessing quality in burns care. This is presented in manuscript form as a research methodology paper and has been submitted to *BMJ Quality and Safety*. I then present a chapter where I bring together the discussions of all manuscripts and synthesise these with the overall findings. I also present the recommendations and ideas for translation into practice as a direct result of this research.

Section D

In this section I list the appendices and provide the references in alphabetical order.

Manuscripts accepted for publication and those submitted to journals for consideration for publication are included where appropriate. As a result, a small amount of the information presented in the front part of the thesis may be repeated in subsequent chapters. A summary of publications and manuscript submissions at the time of submitting this thesis can be seen on pages seven and eight.

SECTION A: A STUDY OF DISCONNECT

This research forms part of a larger NHMRC funded project investigating burns injury in Aboriginal and Torres Strait Islander children. The protocol for this overall study, authored by the investigators and published in *BMJ*, has been provided in Appendix 1. The larger study has various foci including quality, safety, cost and impact of care, along with health outcomes for Aboriginal and Torres Strait Islander children. In this section I introduce the specific focus of my work, exploring burns care within this large project and position it within a space of health inequities. I then describe the epistemological and ontological positioning and theoretical framework for the research. In doing so, I engage a process of reflexivity to highlight the very connected nature of this project.

CHAPTER 1 – Introducing and approaching research about burns care for Aboriginal and Torres Strait Islander children and families

In this chapter I introduce the research and situate it within a domain of health inequities. In doing so, I provide a very basic report of Australia’s colonising history. The aim of this report is to help contextualise this research, not to provide a full historical account of events. I link the experience of health inequities by Aboriginal and Torres Strait Islander peoples to a bigger issue of social justice. I then introduce myself and present the epistemological and ontological positioning that informs the basis of my methodological choices. I begin by explaining my position and discuss how I came to engage with research with and for Aboriginal and Torres Strait Islander peoples. This is my ontology. I then present my understandings of Indigenous ways of knowing, being and doing, along with a description of the ways of white people. These are represented as two different epistemologies and are compared. I follow this with a discussion about how the health outcome inequities experienced by Aboriginal and Torres Strait Islander people can be attributed to differences between the two aforementioned knowledge systems or epistemologies. Factors surrounding the conflict of knowledges, manifest in healthcare, are presented and discussed in relation to this project. This information provides a vital foundation for this research, and consequently this chapter is important in justifying why and how I have come to conduct this research.

An experience of inequities

In Australia, the traditional custodians of the land are the Aboriginal and Torres Strait Islander peoples. Aboriginal and Torres Strait Islander people occupied their land for more than 60,000 years prior to European settlers arriving on *their* shores in 1788 (Reynolds 1981). Preceding this date, Aboriginal and Torres Strait Islander peoples led strong and healthy lives, participated in family and cultural traditions, used their medicines and healing processes, and were guided in their ways by their lore and law (Reynolds 1981, Foster & Nettelbeck 2012). In the years following the arrival of the European settlers, known from this point forward as ‘the settler society’ or ‘white’ people, the life situation and health and wellbeing of Aboriginal and Torres Strait Islander peoples changed.

For the past 230 years white people have taken from Aboriginal and Torres Strait Islander peoples (Reynolds 1981). White people have disempowered, oppressed and aimed to assimilate Aboriginal and Torres Strait Islander peoples (Commonwealth of Australia 1997, Foster & Nettelbeck 2012).

These practices are characteristic of colonisation and have been replicated in multiple settings worldwide and over many centuries (Smith 2012, Anderson, Robson, Connolly et al. 2016). As a result of colonisation, Aboriginal and Torres Strait Islander peoples now experience disproportionally high rates of unemployment and representation in the justice system and there are more children than non-Indigenous children in the child protection system (AIHW 2015). White Australia has been bad for Aboriginal and Torres Strait Islander people's health overall (Sherwood 2013).

The impact on health through the actions of white people has also led to an exceptionally high experience of health outcome inequities by Aboriginal and Torres Strait Islander peoples (Department of the Prime Minister and Cabinet 2017). Health inequities are differences in health outcomes that are unnecessary, avoidable, unfair and unjust (Whitehead 1991). At the heart of inequities as they exist in Australia is the processes of colonisation and a continuation of colonising ideologies.

The health inequities experienced by Australia's Aboriginal and Torres Strait Islander peoples are similar to those experienced by Indigenous people around the world. King, Smith and Gracey (2009, p. 65) state *'…the world's almost 400 million Indigenous people have low standards of health'*. For example, around the world Indigenous peoples suffer a lower life expectancy and experience health outcome inequities at a much higher rate than non-Indigenous people (Anderson et al. 2016). Health outcome inequities are experienced in many domains including infant and young child mortality, maternal morbidity and mortality, infectious disease, social and emotional wellbeing, accidents and lifestyle diseases (King, Smith & Gracey 2009).

In Australia, the evidence of health inequities are reported in numerous reports across a broad range of indicators, including those by the Australian Institute of Health and Welfare (AIHW). The AIHW (2016a) presented the 'Australia's Health 2016' report and provides some of the context for this research project. The age profile of the Aboriginal and Torres Strait Islander population is considerably younger than for the non-Indigenous population. Data for June 2011 (ABS 2011) shows that half of the Indigenous population was aged 22 or under (compared with 38 or under for the non-Indigenous population). Remote areas of Australia are disproportionally populated by Aboriginal and Torres Strait Islander peoples, with 2011 Census data showing that almost half (45%) of all people in very remote areas, and 16% in remote areas, were Aboriginal and Torres Strait Islander peoples, compared with a 3% representation of Aboriginal and Torres Strait Islander people in the total population (ABS 2011). Nevertheless, Aboriginal and Torres Strait Islander peoples were still more likely to live in urban rather than remote areas. Within each state and territory, the proportion of Indigenous people was highest in the Northern Territory (30%); the lowest was 1% in Victoria, and was between 2% and 5% for all other states and territories. ABS

(2011) census reporters acknowledge that for various reasons, not all Aboriginal and Torres Strait Islander peoples are identified in the different data sets, which can lead to an undercount. In 2016, the AIHW reported that Aboriginal and Torres Strait Islander peoples experience higher rates of chronic and preventable illnesses, and self-report poorer health than non-Indigenous Australians (AIHW 2016a). In 2014, the AIHW reported Aboriginal and Torres Strait Islander people can expect to live approximately 10 years less than non-Indigenous Australians (AIHW 2014). These inequities persist despite the continuation of the 'Close the Gap' national policy response that was introduced in 2006. In this document, it was reported that health outcome inequities not only continue to persist, but in many instances, the gap between Aboriginal and Torres Strait Islander peoples' health and that of non-Indigenous people is widening (Department of the Prime Minister and Cabinet 2017).

Aboriginal and Torres Strait Islander children experience comparative health outcome inequities to what is seen in the adult population. The infants of Aboriginal and Torres Strait Islander mothers are twice as likely as those of non-Indigenous mothers to be born of low birth weight (AIHW 2011b). Among different jurisdictions in Australia, the difference between Indigenous and non-Indigenous infant mortality rates ranges from twice as high to almost four times as high in comparison to non-Indigenous infants (AIHW 2011b). Data from South Australia showed Aboriginal and Torres Strait Islander children have almost twice as much dental decay as other children (AIHW 2011b). Aboriginal and Torres Strait Islander children also have the highest prevalence of otitis media among the world's children (AIHW and Australian Institute of Family Studies 2014). In addition to these health inequities, Aboriginal and Torres Strait islander children experience burns injuries at a rate at least double that of other children (AIHW 2011b). Möller, Harvey, Falster et al. (2017) reported similar inequities related to burns injuries.

Not only is there an inequity in the experience of burns injury by Aboriginal and Torres Strait Islander children, health outcome inequities following a burns injury also exist. That is, Aboriginal and Torres Strait Islander children are hospitalised for burns twice as often as other children (AIHW 2012). Aboriginal and Torres Strait Islander children also have longer lengths of stay in tertiary hospitals following a burns injury (Möller, Harvey, Falster et al. 2017).

An experience of such health inequities by Aboriginal and Torres Strait Islander peoples is unequivocally wrong and is a social justice issue. Especially those inequities experienced by children. Given *'the child, by reason of his physical and mental immaturity, needs special safeguards and care'* (UNICEF 1989), something needs to be done to address these inequities. Furthermore, the World Health Organization (WHO) says it is a basic human right that all people have '*the right to health*' (WHO 2017), regardless of cultural or life situation. Additionally, the United Nations' (UN) General Assembly Declaration on the Rights of Indigenous People (UN

2007), reaffirms that Indigenous peoples have the right to the enjoyment of the highest attainable standard of physical and mental health. This is further supported by the assertion in the Convention on the Rights of the Child (UNICEF 1989) Article 6 says that children have the right to live a full life and in Article 24, that children have the right to good quality health care. Of particular importance here is that all Aboriginal and Torres Strait Islander peoples, including children, should expect to experience the same level of health as that experienced by non-Indigenous people across Australia.

While all inequities are important and need addressing as a matter of urgency, this research project is focused on the burns care received following an experience of burns injury by Aboriginal and Torres Strait Islander children. It is not clear how Australia’s health system takes deliberate steps toward the delivery of appropriate burns care for Aboriginal and Torres Strait Islander children. Given the UN Convention on the Rights of the Child (UNICEF 1989) assertion to protect children who experience injury through appropriate and safe healthcare, an investigation of burns care for children is relevant. Furthermore, the WHO’s assertion that human rights includes receiving care that is timely and appropriate (WHO 2017) makes this research important.

This investigation of burns care for Aboriginal and Torres Strait Islander children who experienced burns injury at disproportionally higher rates than non-Indigenous children (AIHW 2011b), is part of a large NHMRC funded project investigating burns injury in Aboriginal and Torres Strait Islander children. I now explain how I became part of this project, and how I, as a non-Indigenous white woman, can do research with, and for, Aboriginal and Torres Strait Islander peoples.

Who am I and how can I do research with, and for, Aboriginal and Torres Strait Islander peoples?

I come to this research as a non-Indigenous woman and registered nurse. I grew up with my family in a small country town in South Australia surrounded by predominantly European settler farming families. I attended and completed my schooling at the local mainstream primary and secondary schools. The first contact I remember having with Aboriginal people was as a child with three Aboriginal children from a nearby coastal town. These children attended the school that I attended for approximately one year. I recall being interested in these children and somewhat befriending the sibling who was my age. I also recall a conversation with my friend about him being known as a ‘Nunga’, and how that was different to ‘Narrunga’. I was told by him that Narrunga is the family group name for this particular region and that Nunga was a term used by some people to describe Aboriginal people from South Australia. I also remember my friend explaining to me that an older child who also lived with his family was not his ‘real’ brother, even though my friend referred to this older child as his brother. I now realise that this was my first increased understanding about kinship. These lessons, whilst specific to the Aboriginal people from a regional South Australian area, could now be considered the start of my journey in learning about the ways of knowing, being and doing of Aboriginal and Torres Strait Islander peoples.

The area of country South Australia in which I grew up was overtly racist and I recall that even as a child I knew something was wrong. I felt uncomfortable. I saw and heard racism in my school life, through my engagement in sporting clubs and in my family's social group. Some examples I recall include the vehicle that the local Aboriginal children caught a ride in to attend sport being referred to as the 'boong bus'; non-Indigenous children on my school bus not letting the three Aboriginal children sit next to them, and hearing adults refer to Aboriginal people as 'gins' and 'darkies', and general derogatory talk.

A transparent practice in Indigenous research settings is presenting one's standpoint and agenda upfront (NHMRC 2003). An explanation of who we are and where we come from, and our motivations, is an integral part of respectful research. This includes who I am as an individual and as a professional and recognising that where I come from is intergenerational. In principle, my motivation to become involved in this research project was because of my longstanding interest in Aboriginal and Torres Strait Islander peoples and their culture, and more recently, an awareness of their unfair experience of poorer health outcomes than those experienced by other Australians. I am now interested in contributing to improving the health outcome inequities experienced by many Aboriginal and Torres Strait Islander peoples, especially those experienced by Aboriginal and Torres Strait Islander children.

My undergraduate tertiary education, a Bachelor of Nursing, was completed in metropolitan Adelaide. This education has provided the foundation of my Western biomedical way of knowing, being and doing, especially as it relates to the provision of healthcare. After working as a registered nurse in the acute sector, I completed post-graduate study in child and family health and changed employment to work with young mothers and families in the northern suburbs of Adelaide, many of whom identified as Aboriginal. My interest in child health developed as a result of my increased curiosity and awareness of the importance and influence of caregivers and families on child health. My work with many of the Aboriginal families taught me more about Aboriginal kinship structures and the significance of shared responsibilities in child rearing. I learnt that kinship is paramount to the wellbeing of Aboriginal and Torres Strait Islander children whereby extended family are significant contributors to raising children.

Since 2013 I have been employed at the Aboriginal Health Council of South Australia. In this organisation I have had (and continue to have) the honour of working with, and for, Aboriginal people in and from numerous communities across South Australia. My work involves health training and primary health care nursing and for the majority of time, contributing to quality improvement in health service delivery. This work is with Aboriginal and non-Indigenous people in the community controlled healthcare sector.

I have been able to use the knowledge from my registered nursing degree and the knowledge gained from working with Aboriginal families to contribute to my work. The work has enhanced my understanding about culture and respect, and very importantly, about reciprocity. Reciprocity is the practice of exchanging for mutual benefit (NHMRC 2003). Reciprocity relates not only to this research project but more broadly to my development and understanding of Aboriginal and Torres Strait Islander people's ways of being and doing. This is most often evident in my work at the Aboriginal Health Council of South Australia and with Aboriginal health workers and practitioners in health services. I am offered, and subsequently gain, insight into Aboriginal and Torres Strait Islander ways of knowing, being and doing, and with my knowledge of, and skills in healthcare I offer insight or support in return. My knowledge of Aboriginal ways of knowing, being and doing develops each day of this research project and continues to do so each and every day in my work. It is a continual journey.

While I did have aspirations to complete a PhD one day, I was not actively seeking out the opportunity to do so. However, in early 2015 I was presented with an offer to become involved in this large NHMRC funded research project as a research assistant and PhD student. I understood then that to complete research with a focus on Aboriginal and Torres Strait Islander health would require significant input from, and connection with, local Aboriginal people. I sought the opinion of two Aboriginal people whom I had (and still have) a very close relationship with to help with my decision. I was reminded that I would most importantly need (and have a desire) to invest time in and learn more about Aboriginal and Torres Strait Islander peoples' ways of knowing, being and doing. After considering my (then) current and past experience, I decided to accept the offer.

These explanations about myself give an insight into my ontological foundation and what the nature of reality (Denzin & Lincoln 2000, p. 19) is for me as a researcher. I am an outsider to the colonised experience and write and do this research as a privileged white woman. However, I have a strong sense of social justice and respect for multiple ways of knowing, being and doing.

The importance of reflexivity in research

Epistemology is the study of knowledge, concerned with how a person comes to know what they know (Denzin & Lincoln 2000, p. 18). This research project is about burns care for Aboriginal and Torres Strait Islander children. The epistemological constructs associated with healthcare for these children are central to this research and will be explored throughout this chapter. A researcher's epistemological stance shapes the methodology, methods and the theoretical frameworks applied (Denzin & Lincoln 2000, p. 18, Moreton-Robinson 2013). As a result, the production of new knowledge and research outcomes are fundamentally defined by epistemology. Defining one's epistemology is a critical starting point in health research (Ellis & Bochner 2000, p. 733-739). To identify and articulate one's epistemology and associated concepts clearly, Crotty (1998) suggests addressing: 1. epistemologies; 2. theoretical perspectives; 3. methodologies; and 4. methods. In this thesis I follow and document these concepts as a sequential research process and begin by exploring epistemologies and ontologies in this chapter. Before this, I present the notion of reflexivity, and how it supported an exploration of mine (and others') knowledge.

No research is without bias (Patton 2015, p. 57-58). This is because researchers bring their ingrained values and beliefs, not often obvious, yet developed throughout life and learnt from surrounding social constructs, to the research process (Patton 2015, p. 7-58). Reflexivity, commonly used as part of a critical approach (Jootun, McGhee & Marland 2009, Wilson 2014), is a process where researchers place themselves and their practice under scrutiny, acknowledging the bias's that might infiltrate the research processes and therefore shape the creation of knowledge (Browne & Varcoe 2006, Dowling 2006). A thorough initial exploration of my bias's in the first part of this thesis has provided the basis for understanding and positioning myself in the research process (Denzin & Lincoln 2000, p. 389).

This research has a focus on burns care for Aboriginal and Torres Strait Islander children and the basis of my being and knowing as a non-Indigenous registered nurse is situated in Western biomedical knowledge. As such, engaging in reflexivity in research meant asking questions about how my personal history led to the interest in this topic and resulted in enabling me to examine my own ideology, history and motivations (Browne & Varcoe 2006, Dowling 2006). Exposure to Aboriginal ways of knowing, being, and doing, with a capacity to reflect critically and consistently on myself, has been facilitated through the essential support of Aboriginal and Torres Strait Islander peoples. This is an important component of reflexivity and evidence of a continuing critique of my standpoint is clear throughout the thesis and will help create transparency and increase the fidelity of the research. Engagement in reflexivity has also supported the conscious revelation of the role of the beliefs and values I hold as the researcher in the selection of research methodology for the generation of new knowledge (Browne & Varcoe 2006, Dowling 2006).

Epistemologies and ontologies – different ways of knowing, being and doing exist and collide

I will now present my understandings of Indigenous ontologies and epistemologies and Western ontologies and epistemologies. In doing so I will explore the different ways of knowing, being and doing of the two knowledge systems. This is important given this research is about burns care, mostly derived in Western biomedical health settings, for Aboriginal and Torres Strait Islander children and families. Exploration of the two knowledge systems, Indigenous and Western, will begin here, yet considerations will continue and be evident throughout the entirety of the thesis.

Indigenous people exist all around the world (WHO 2007).

> *They are the descendants - according to one definition - of those who inhabited a Country or a geographical region at the time when people of different cultures or ethnic origins arrived, the new arrivals later becoming dominant through conquest, occupation, settlement or other means (UN High Commissioner for Human Rights).*

While there are differences between Indigenous groups, such as their degree of dispossession and experience of some health inequities, commonalities exist (Anderson et al. 2016). Commonalities include such things as a lack of basic human rights, a claim to self-determination and a connection to the environment (Durie 2005). Durie describes the primary characteristic of indigeneity as *'enduring relationship between populations, their territories, and the natural environment'* (2005, p. 302). He describes the five secondary characteristics of this primary connection to the land as: enduring over time, celebrated, a source of knowledge, facilitator of balance and a contributor to unique language (Durie 2005, p. 302). Aboriginal and Torres Strait Islander peoples are Australia's Indigenous people and are someone who: is of Aboriginal descent; identifies as an Aboriginal person, and is accepted as an Aboriginal person by the community in which he or she lives (Australian Human Rights Commission 2012). In 2016, 3.3% of all Australians identified as Aboriginal and/or Torres Strait Islander (ABS 2016).

Prior to colonisation in Australia by the settler society, Aboriginal and Torres Strait Islander peoples lived on, were taught to know, and thrived on the land they called 'Country' for many thousands of years. Important practices around family, life, medicines, law and lore were engaged and good health was experienced (Pascoe 2018). Purdie, Dudgeon and Walker (2010) describe Aboriginal and Torres Strait Islander people's deep connection to Country as being a collective and individual connection. 'Country' is where family groups feel belonging, where boundaries are determined by the actions of spiritual ancestors and known through Dreaming stories (Purdie, Dudgeon & Walker 2010). Hence, Country is where a person belongs, not something they own (Purdie, Dudgeon & Walker 2010). Data from 2012-2013 estimated that 25% of Aboriginal and Torres Strait Islander adults lived on land they called their Country (AIHW 2015). A connection to Country is enduring, and as such remains fundamentally integral to health and healing for Aboriginal and Torres Strait

Islander peoples regardless of where they reside. This contrasts with white people in Australia who have historically engaged in exploiting the Australian land for individual, social and economic gain (Pascoe 2018). The connection and custodianship to land and to the environment that Indigenous peoples possess, contrasts with white standpoints of belonging and ownership. In contrast to Indigenous ways of placing Country ahead of, or alongside, other needs and in close reciprocal relationships and connection, white ways of relationship to Country have placed other needs ahead of that of Country (Moreton-Robinson & Walter 2009, p. 5).

There are multiple ways in understanding and using knowledge. In many ways and in glaring contrast to Indigenous peoples, are the ways of being and knowing of white people (Smith 2012), especially as it relates to health and healing. Science is the dominant global knowledge system of white people (Moreton-Robinson & Walter 2009, p. 3) and is often understood to be individualistic and limited by its capacity to be responsive to other ways of knowing. This contrasts with Indigenous knowledge production that is valued for being both communal and collective (Moreton-Robinson & Walter 2009, p. 4, Muller 2014, p. 69). Scientific evidence informs constructs of power, ownership and beliefs of health and healing. Australia was founded on scientific evidence which was subsequently widely employed to preserve white Australia's dominant position. This is especially the case in healthcare. In Australia, white people predominantly employ a Western biomedical perspective to health that is informed by scientific evidence (Taylor & Guerin 2014, p. 107, Best & Fredericks 2018, p. 56). This evidence has led to some of the most outstanding advances in medical healthcare across the world. Advances include cures for cancer, improved diagnostic abilities, telehealth capabilities and cutting-edge surgical technology (Taylor & Guerin 2014, p. 107). However, such evidence often fails to consider any other construct of health and healing (Taylor & Guerin 2014, p. 108). The normative approach to healthcare in Australia is founded on the Western biomedical model (Best & Fredericks 2018, p. 56) which segregates wellbeing into parts, and therefore contrasts with the holistic standpoint of Aboriginal and Torres Strait Islander peoples (Taylor & Guerin 2014, p. 112). Helen Milroy describes the holistic health model integral to Aboriginal and Torres Strait Islander people's as a multi-dimensional concept that includes physical, psychological, social health and wellbeing, spirituality, and cultural integrity (Australian Indigenous Doctors' Association 2010).

The powerful and dominant ways of white people through colonisation, and of scientific evidence believed as the absolute truth, has given rise to unfair experiences of privilege for white people. Eckermann et al (2006) reported that Western scientist Charles Darwin presented a concept of human existence whereby humans existed on a scale from being civilised, through to primitive. In this, white or fair-skinned people were considered as being the most civilised and at the top of the hierarchy. Subsequent scientific research presented anyone other than civilised, as something different, leading to deficit assumptions and stereotypes of dark-skinned peoples as less than their civilised counterparts. Such examples of scientific evidence further inform the notion of white people being ‘normal’. That is, white people perceive themselves as normal, are aware of races and of people with colour, and see others as having a race. This is what is described as whiteness and gives white people privileges not experienced by people of colour (Taylor & Guerin 2014, Moreton-Robinson 2015, pp. 65-66). Indigenous, or dark-skinned people on the other hand, do not experience these same privileges.

> *Whiteness in its contemporary form in Australian society is culturally based. It controls institutions, which are extension of white Australian culture and is governed by the values, beliefs and assumptions of that culture and its history. Australian culture is less white than it used to be… (Moreton-Robinson 1999, p. 28).*

Whiteness informs and is commonly referred to in public discourse about healthcare as mainstream (Moreton-Robinson 2015, p. 28). Mainstream healthcare is supported by the scientific evidence informing the Western biomedical model which intern governs what is considered ‘best’ care for all people accessing care (Taylor & Guerin 2014, p. 80). However, what is not clear is if the Western biomedical model provides ‘best’ care at all. The relevance of this dominance of ways of knowing, being and doing to this research is that for a serious burns injury it is necessary for Aboriginal and Torres Strait Islander children and families to access mainstream burns care.

Colonisation and its impact on healthcare and health outcomes in Australia, especially for Aboriginal and Torres Strait Islander children

Conflicts have been identified in the exploration of the two ways of knowing, being and doing, especially as they related to health and healing. This incongruence between knowledge systems was and continues to be the fundamental driving force underpinning colonisation in Australia (Smith 2012, Moreton-Robinson 2015). Indigenous authors describe the process of colonisation as an invasion, where white people invaded countries and stripped Indigenous people of their rights to maintain their ways of knowing, being and doing (Smith 2012, Moreton-Robinson 2015). Colonisation was when white people forbade the use of traditional Indigenous language, removed children, dispossessed individual and whole families’ groups of land, and oppressed culture (Smith 2012, Moreton-Robinson 2015). The driving force behind colonisation is described as being rooted within the idea that Indigenous knowledges are inferior to Western knowledges (Smith 2012, Moreton-Robinson 2015) and in the belief that white ‘ways’ are superior to all other ways of knowing, being and doing (Smith 2012, Moreton-Robinson 2015). It is from this belief, and upon subsequent imbalances in power relations that colonisation has been built. I will now explore the detrimental impact of colonisation on healthcare and health outcomes for Aboriginal and Torres Strait Islander peoples in Australia.

In Australia, the belief that the land belonged to no one informed the founding principles of the relationship between Aboriginal and Torres Strait Islander peoples and the settler society (Martin

2003, p.203). The land we currently call Australia, was deemed ‘terra-nullius’, meaning land that was legally deemed to be uninhabited (Commonwealth of Australia 1997, Martin 2003, p. 203). The subsequent development of white policy by white people acted to exclude Aboriginal and Torres Strait Islander peoples from being citizens and situated white people in a position of power (Muller 2014, p. 72). These policies continue to contribute to the mistrust by Aboriginal and Torres Strait Islander peoples of white people today, especially as they relate to accessing healthcare (Moreton-Robinson 2015). This is important background for this study as it is necessary for those experiencing a serious burns injury to access specialist mainstream healthcare (Herndon 2017). Similarly, there are implications for Aboriginal and Torres Strait Islander peoples accessing burns care given white healthcare professionals make up the majority of those people employed and working in Australia’s mainstream healthcare system (Best & Fredericks 2018, p. 56). It is further compounded by the structure and delivery of mainstream services that have been developed though Western scientific evidence (Moreton-Robinson 1999).

The marginalised position of Aboriginal and Torres Strait Islander peoples relative to mainstream society in Australia is linked to their poor health status (Marmot, Friel, Bell et al. 2008). The health outcome inequities suffered by Aboriginal and Torres Strait Islander peoples has been linked to experiences of interpersonal racism and to racism as a persistent obstacle in accessing healthcare (Durey 2010). Institutionalised racism has been described as widespread within the contemporary Australian healthcare system, along with funding levels that do not correspond with levels of health disparity (Henry, Houston & Mooney 2004). The power of the Western biomedical paradigm in Australia has resulted in the current healthcare system being predominantly resourced and focused on medical intervention (Durie 2004). The structure and characteristics of, and an emphasis on and application of, predominantly scientific medical interventions in Australia’s healthcare system has contributed to the current poor health of many Aboriginal and Torres Strait Islander peoples (Dudgeon, Milroy & Walker 2014, Taylor & Guerin 2014, Best & Fredericks 2018).

Strategies like ‘Close the Gap’ as implemented by the Australian Government have made some positive impact on the health outcome disparities experienced by Aboriginal and Torres Strait Islander peoples, including life expectancy and child mortality; however issues of inequities and long-standing challenges remain across all domains (Department of the Prime Minister and Cabinet 2017). Many factors contribute to the gap between Indigenous and non-Indigenous peoples’ health. Social disadvantage, such as lower education and employment rates, is a factor, as well as higher smoking rates, poor nutrition, physical inactivity and poor access to health services.

Difficulties in accessing care

There are ways in which Aboriginal and Torres Strait Islander peoples experience unique disadvantage in their access to and interactions with mainstream health systems. This includes white healthcare professionals who often have world views and beliefs about health and healthcare that are often different from their own (Dwyer, Kelly, Willis et al. 2011, Kelly, Dwyer, Pekarsky et al. 2012). There are well-documented barriers to access at both primary and tertiary healthcare services for Aboriginal and Torres Strait Islander peoples in urban, rural and remote areas (Cunningham 2002, Attwood, Rodrigues, Winsor et al. 2015, Tavella, McBride, Keech et al. 2016). Numerous studies highlight delays for Aboriginal and Torres Strait Islander peoples in accessing tertiary care, suggestive of problems with the interface between primary and tertiary care systems (Scrimgeour & Scrimgeour 2008). This is a direct result of the inability of the two knowledge systems to work together.

Due to reported health inequities, Aboriginal and Torres Strait Islander peoples could be expected to access health services at much higher rates than non-Indigenous Australians, however this is not the case. Comparable data suggests that overall access to health services for Aboriginal and Torres Strait Islander peoples is only marginally higher than that for non-Indigenous people (Australian Health Ministers' Advisory Council 2012). This is also the case for health expenditure in the period 2010-2011 (AIHW 2015) which was only marginally higher for Aboriginal and Torres Strait Islander peoples than for non-Indigenous peoples. Furthermore, Medicare and pharmaceutical benefits were lower in this period for Aboriginal and Torres Strait Islander peoples than for non-Indigenous peoples (AIHW 2015). In 2015, the AIHW reported that experiences of unfair treatment by healthcare professionals meant that 7% of Aboriginal and Torres Strait Islander peoples avoided seeking healthcare in the period 2012-13 (AIHW 2015).

While service use and spending patterns give some indication of the demand for health services, they do not provide information on whether services are accessible or appropriate to all who need them, nor do they give a complete picture of whether the health needs of populations are being met. For example, even though an Aboriginal and Torres Strait Islander person may have physical access to a service, financial, social and cultural factors may influence whether care is accessed or not. Similarly, there is the possibility that availability of healthcare may not necessarily mean that it is the most suitable care for the health needs of Aboriginal and Torres Strait Islander peoples.

The accessibility of high-quality care for Aboriginal and Torres Strait Islander children is particularly important. This is because they constitute a high proportion of burns patients (AIHW 2011b, Möller et al. 2017) and given the complexity of long-term burns care (Herndon 2017), access to best quality treatment is essential to produce good long-term outcomes, (Kim, Martin & Holland 2012, Herndon 2017). There are some documented ways in which the delivery of healthcare in general can be improved for Aboriginal and Torres Strait Islander children (Milroy 2008, Attwood et al. 2015). These include through culturally competent healthcare (Bainbridge, McCalman, Clifford et al. 2015) resulting in an experience of culturally safe healthcare. Nonetheless, an investigation of issues related to healthcare for Aboriginal and Torres Strait Islander children requiring burns care, including those synonymous with geography, appropriateness and acceptability as contributing factors to poorer healthcare access is still required.

Cultural competence as key to improving access to healthcare

There is a lack of robust evidence regarding cultural competency in healthcare leading to better health outcomes for Aboriginal and Torres Strait Islander peoples (Bainbridge et al. 2015). It is therefore not that surprising that no clear information exists regarding how burns care in Australia is addressing or achieving cultural competence. However, there is much written about how cultural competency is a fundamental approach to improving access to healthcare and the quality and effectiveness of care for Aboriginal and Torres Strait Islander peoples (Commonwealth of Australia 2013). Cultural competence in healthcare is the ability of health systems to support the provision of best care to patients with diverse values, beliefs and behaviours including tailoring delivery to meet a patient's social, cultural and linguistic needs (Bainbridge et al. 2015). A definition such as this, positions cultural competence as an overarching attribute that is achieved through various means. Evidence derived from the Kanyini study found that if you approach care in the right way, Aboriginal and Torres Strait Islander peoples will access care (Howard, Ingram, Liu et al. 2014). This is supported by an Australian governmental report that said, '*cultural competency is a key strategy for reducing inequalities in healthcare access and improving the quality and effectiveness of care for Indigenous people*' (Bainbridge et al. 2015, p. 2). However, this report concluded that more work is required to confirm effectiveness and to determine what constitutes best strategies for achieving cultural competence (Bainbridge et al. 2015).

Cultural safety as an experience of care

It is not clear if or how burns care is providing care that is experienced as culturally safe for Aboriginal and Torres Strait Islander children. Cultural safety is an experiential, contextual theory developed by Maori in the New Zealand healthcare context to address the ways in which colonial practices, organisations and policy shape and negatively affect the health of Maori peoples (Ramsden 2002). The theory has since been adopted in other countries including Canada (National Aboriginal Health Organization 2008) and Australia (Bainbridge et al. 2015), with evidence of improved healthcare outcomes (Bainbridge et al. 2015). The five principles of cultural safety includes: reflexivity – reflecting on practice with mutual respect; dialogue – true engagement and consultation; power – minimising power differentials and maintaining human dignity; decolonisation – acknowledging the key role of a colonising history in shaping contemporary health outcomes for Aboriginal and Torres Strait Islander peoples; and regardful care – provision of care that is regardful of culture and challenges the status quo of providing care that is regardless of culture (Taylor & Guerin 2014). An emphasis of cultural safety is on the healthcare interaction where it is the individual health professional’s level of empathy and reflective practice capacity that is, or is not, experienced as culturally safe (Ramsden 2002, Richardson & Carryer 2005). These qualities, empathy and reflective practice capacity, contribute to a health professional’s understanding of the process of culture and identity and how power imbalances or relationships contribute to culturally safe or unsafe practice (Richardson & Carryer 2005).

The prolific advancements in burns care that has led to reduced morbidity and mortality are based on surgical intervention and scientific evidence derived in a Western biomedical paradigm (Herndon 2017). This study is about burns care for Aboriginal and Torres Strait Islander children who suffer disproportionally from burns injury in comparison to non-Indigenous children. It is not clear how burns care in Australia considers the needs of this overrepresented and important population. While medical and surgical interventions are vital to burns care (Herndon 2017), these interventions are informed by only one part of the system of knowledge. It is not clear if or how other knowledges may form a foundation knowledge base to treat burns and contribute to improved outcomes and healthcare experiences, nor inform any aspect of care for these children.

Chapter summary

With the focus of this study being burns care for Aboriginal and Torres Strait Islander children, it was important to consider how burns care for Aboriginal and Torres Strait Islander children ‘finds its place’ in Australia’s mainstream, predominantly Western biomedical healthcare system. To do this, the past and current Australian situation in terms of the dominant culture and subsequent healthcare system must be reflected upon. This therefore includes a consideration of white people as part of the dominant culture of Australia and the subsequent Western biomedical healthcare system. Reflection on colonisation, whiteness, white privilege and racism in relation to Australia’s healthcare system was necessary. As such, in this chapter I introduced myself as a white woman, educated in a Western biomedical paradigm as a registered nurse. Importantly, I presented my positioning and place in this research and discussed how I have used reflexivity throughout the research process to ensure my biases, and any impact on the research are clear. I presented the key constructs of Indigenous and Western ways of knowing, being and doing and discussed how history has led to how they are at play in Australia today. While there have been significant attempts at addressing health inequities, gaps in health and wellbeing remain disturbingly high (Department of the Prime Minister and Cabinet 2017). This research sits at the interface of a disconnect in ways of knowing, being and doing that does not enable the full access to quality care for Aboriginal and Torres Strait Islander peoples.

CHAPTER 2 – Theoretical Framework for burns care research with and for Aboriginal and Torres Strait Islander children and families

Chapter one made clear a disconnect between knowledges in Australia as a driving force behind the inequities experienced by Aboriginal and Torres Strait Islander peoples. However, there is much more to inequities than a disconnect between knowledges as extreme differentials in power exist within these knowledge regimes. As colonisation is fundamentally grounded in imbalances of power which in turn determines what is true, right and real, colonisation also influences inequities. This research is focused on exploring burns care and to make recommendations about how to mitigate any conflict of knowledges that may be present in healthcare as it relates to burns care for Aboriginal and Torres Strait Islander children. In exploring burns care, I examined theories from both Western biological and Indigenous peoples' constructs of health and healing and aimed to identify where they cross over or 'interface'. In doing so, I chose to investigate the interface of knowledges using theories that sit behind components of thedisconnect. In this chapter I describe the theoretical frameworks and methodology used to guide this research project. I begin with introducing this as a broad qualitative research project. I then start with exploring postcolonial theory and discuss how it does not fully address a critical or decolonising agenda. Next, I present ideas about critical race theory and how this too goes some way towards addressing power imbalances but does not fully account for a decolonising approach either. Furthermore, critical race theory is based on a civil rights and the law, and is not based in health, as is the motivation for this research. Following this I present the Indigenous theories relevant and appropriate to this research project. I review these theories and concepts within a decolonising approach to research and argue how interface research methodology is most appropriate to guide this research project. In doing so, I also introduce the theory of Ganma and important ontological constructs around Aboriginal and Torres Strait Islander people's health and healing as they relate to healthcare delivery in Australia.

A broad qualitative research project

Western traditions have come to investigate matters related to the lived experiences of peoples and culture using qualitative methodologies (Denzin & Lincoln 2000). Qualitative methodologies or strategies of inquiry (Denzin & Lincoln 2000) provide a way to investigate '*real people in real situations*' (Patton 2015, p. 13). As this research aims to explore burns care by multidisciplinary burns team members engaged in providing care in tertiary healthcare institutions for Aboriginal and Torres Strait Islander children and families, a qualitative approach is appropriate.

Qualitative research is not mathematical as is the focus of quantitative research whereby data is quantified. Data drawn through qualitative methods provides contextual information and rich insight into human behaviour (Patton 2015, p. 13). Qualitative data can help avoid the ambiguities surrounding generalisations that may have statistical significance but little individual applicability (Denzin & Lincoln 2000, p. 786). This is important for this research given that burns care for Aboriginal and Torres Strait Islander children and families, needs to address their constructs of health and healing, and not be generalised within Western mainstream methods of healthcare.

The findings from qualitative research offer insight into the conditions, values, needs and preferences of those research participants (Patton 2015), and as such will support exploration those things that inform burns care. Furthermore, qualitative approaches acknowledge that situational constraints shape inquiry and that the research is filtered through the eye of researcher and is therefore interpretive (Patton 2015). Therefore, the exploration of who I am, as the researcher, was and is important as this further highlights the significance of reflexivity in research.

Qualitative approaches highlight the very relational nature inherent in research and as such provide an appropriate, yet broad approach relevant to this research project. Furthermore, a qualitative study design provides some of the basic principles for the interfacing of Western and Indigenous knowledges though the consideration of people's experiences and culture. This is especially important given my non-Indigenous identity. Qualitative approaches to research focus on the socially constructed nature of reality and as such, further exploration of what qualitative theories can bring to the research is important.

Relevance of postcolonial theory

Postcolonial theory is concerned with the history of colonialism and its ongoing relevance to people's lives (Browne, Smye & Varcoe 2005, p. 17). The theory presents a requirement to '*revisit, remember and interrogate the colonial past and its aftermath in today's context*' (Browne, Smye & Varcoe 2005, p. 20). Postcolonial theoretical frameworks provide critical cultural perspectives that question the thinking behind cultural policies and the extent to which they address historical and ongoing impacts of colonisation, disadvantage, marginalisation and 'othering' (Browne & Varcoe 2006, Sherwood & Edwards 2006). That postcolonial theory is concerned with an interrogation of past events and their relevance to current health outcome inequities makes the theory relevant to this research project. Further still, postcolonial theory in the research context describes the continuous struggle of Indigenous peoples resisting the overpowering of their ways of knowing by Western knowledge.

Critiques of postcolonial theory centre on a number of issues (Browne, Smye & Varcoe 2005, p. 24-25). Browne, Smye and Varcoe (2005, p. 24) report that postcolonial theory partly ignores how social experiences, context and situation influence knowledge creation. It does this partly through limited consideration of capacity of resistance and agency of the oppressed (Browne, Smye and Varcoe 2005, p. 24). Essentialisation of groups of people often results in important differences and unique experiences being overlooked and is an additional critique of postcolonial theory (Browne, Smye & Varcoe 2005, p. 25). An example of this is discussed by Downing et al. (2011) who suggest that essentialising causes issues for cultural competence training whereby participants of training are provided with only a narrow understanding of what Indigenous culture is. In addition, the word 'post' can be interpreted or suggest that colonialism has ended (Browne, Smye & Varcoe 2005, p. 20). However, as Smith argues '…*the institutions and legacy of colonialism have remained*' (2012, p. 98). Struggles of oppression, marginalisation and racism continue (Henry, Houston & Mooney 2004, Durey 2010, Priest, Paradies, Gunthorpe et al. 2011). In Australia for example, overt racism remains present in Australian society and is normalised on a continual basis with many Aboriginal and Torres Strait Islander peoples experiencing racism on an everyday basis (Priest et al. 2011). Similarly, structural and systemic racism is at the core of mainstream healthcare policy and systems (Henry, Houston & Mooney 2004). Paradies (2018) provides further evidence for the continued existence of racism in many aspects of current Australian society.

Postcolonial theory addresses some of the critical elements pertaining to the colonisation of Indigenous peoples' knowledge and identity. The theory provides some direction for research with Aboriginal people through understanding how the past impacts the future and the colonising potential of research. Postcolonial theory also provides the means to consider the context in which healthcare is delivered in Australia. These approaches are relevant to this research project, however because postcolonial theory is limited in its ability to take full account of Indigenous knowledges, and as the interfacing of knowledges as is required in this research project, additional theories are essential.

Critical race theory and it's applicability to this research

Critical race theory (CRT) is based on a socially constructed phenomena (Patton 2015, p. 692). A socially constructed phenomena is something that seems normal to and is accepted by people but may or may not represent reality (Burr 2015). Use of CRT in research offers the opportunity to challenge established knowledge systems and to investigate social situations and how society organises itself along racial lines and hierarchies and to then transform it (Patton 2015, p. 692). Those researchers who engage a critical approach are acutely aware of the need for research to foster emancipation, while addressing power imbalances to give those formerly marginalised, a voice (Denzin & Lincoln 2000, p. 281-282).

A critical researcher '*is one who uses their work to critique the social, cultural and political environment*' (Sherwood 2010, p. 109). Given this research is about investigating burns care for Aboriginal and Torres Strait Islander children, a marginalised population in Australia's healthcare system (Best & Fredericks 2018, p. 13-14), a critical theory is relevant. However, core to the developed of the CRT was the legal argument to ban segregation and slavery in the United States of America (Ladson-Billings 1998). Therefore, the theory was born of place of law and oppression (Ladson-Billings 1998), but not about health or a denial of sovereignty as is the case for Aboriginal and Torres Strait Islander peoples. Nonetheless, it has been applied in Australian contexts such as in higher education on the subject of critical whiteness (Nicoll 2004), antiracism research (Ford and Airhihenbuwa 2010) and used as a framework for population health research (Graham et al 2011). Furthermore, while CRT examines citizenship through many complex connections (Ladson-Billings 1998), in Australia when this theory was developed, Aboriginal and Torres Strait Islander peoples were not even considered citizens by colonial standards and law. So, while CRT provides a means to address structural power imbalances, the theory is polarising and does not support a research approach that holds multiple world views as equally important, as is this case in this research.

Indigenous theories and research with and for Aboriginal and Torres Strait Islander peoples

As a non-Indigenous registered nurse educated in a Western biomedical paradigm and engaging with rational scientific approaches to healthcare, the use of Indigenous theories alone to investigate burns care for Aboriginal and Torres Strait Islander children is unsuitable and inappropriate. It would be equally as challenging to solely apply Western theories to research with and for Aboriginal and Torres Strait Islander peoples and concerning their ways of knowing and being. This would also be fundamentally wrong given the misrepresentation of Indigenous knowledges by Western theories in the past (Smith 2012). In this section, I present my exploration of Indigenous theoretical positions, with a particular focus on Aboriginal and Torres Strait Islander theories that will facilitate inclusion of Aboriginal and Torres Strait Islander research constructs into this inquiry.

Indigenous standpoint theory

Misrepresentation of Indigenous knowledge in the past (Martin 2003) has resulted in many Aboriginal and Torres Strait Islander researchers and theorists reframing Western research in order to develop and describe their own paradigms (Martin 2003, Nakata 2007, Moreton-Robinson 2013). Nakata was instrumental in his contribution to Indigenous standpoint theory (Moreton-Robinson 2013) and has since been further developed by Paradies (2018). Indigenous standpoint theory describes Indigenous people's connectivity with all living things, so that the body and

Country are one and the same. Indigenous standpoint theory accepts the collective is just as important as the individual, and also that there is an enduring relationship with nature that informs knowledge creation. These are the fundamental tenants of Indigenous standpoint theory, and show how an Indigenous person is placed in the world (Nakata 2007). Moreton-Robinson recognised the struggle of gender in research and built on Nakata's work. She described an Indigenous women's standpoint theory influenced by the intersecting oppressions experienced by Indigenous women (Moreton-Robinson 2013).

Indigenous ways of knowing are relational and understood through dimensions of interaction, continuity and situation (Moreton-Robinson & Walter 2009). Spirituality *'is an integral aspect of the ways in which any Indigenous people understand the world'* (Muller 2014, p. 78), and integral to Indigenous theories. Indigenous researchers '*incorporate cultural/metaphysical aspects of Indigenous knowledges*' (Muller 2014, p. 79) and aim to assert Indigenous sovereignty in research (Denzin & Lincoln 2000). Knowledge creation with Indigenous theories that have less restriction and more flow than Western scientific theories, can be loosely linked to postcolonial theory that is driven by similar ideologies (Moreton-Robinson & Walter 2009).

Indigenous health and healing as a theory

The ways of knowing, being and doing for Aboriginal and Torres Strait Islander peoples are different to those of non-Indigenous peoples (Martin 2003). This includes notions of health and healing. As mentioned in chapter one, Helen Milroy describes the holistic health model integral to Aboriginal and Torres Strait Islander peoples as a multi-dimensional concept that includes *physical*, *psychological*, *social health and wellbeing*, *spirituality* and *cultural integrity* (Milroy 2006). This model has previously been used to critique and explore the impact on health of government policy in the Northern Territory of Australia (Australian Indigenous Doctors' Association 2010). It was successful here in giving a voice to affected communities, provided suggestions for improvements and aimed to lessen negative impacts on health and wellbeing (Australian Indigenous Doctors' Association 2010).

The theory of cultural safety

Cultural safety was described in the previous chapter predominantly as an experience of care (Taylor & Guerin 2014, Best & Fredericks 2018) whereby I described how access to healthcare can be measured against a person's experience of culturally safe care. The use of cultural safety as a theory in research can be a useful tool due to its *'potential to focus on power imbalances and inequitable social relationships in health care; the interrelated problems of culturalism and racialization; and a commitment to social justice*' (Taylor & Guerin 2014, p. 111). The theory of cultural safety and its five elements have been used in the Australian research context (Mackean, Fisher, Friel et al. 2019). Mackean et al. (2019) research resulted in the development a cultural safety framework to guide assessment of policy and was found to be relevant for critical analysis of Australian policy affecting Aboriginal and Torres Strait Islander peoples. As such, the relevance of the theory of cultural safety and its five principles: reflexivity, dialogue, power imbalances, regardful care and decolonisation, to this projects is clear.

Decolonising theory to ensure full consideration of Aboriginal and Torres Strait Islander peoples' ways of knowing, being and dong

For Indigenous researchers, Linda Tu-Smith writes powerfully about the need for decolonising methodology (Smith 2012). This is because most existing research investigating Indigenous peoples is contaminated by Eurocentric biases (Muller 2014, p. 68) and done *on* and *to* Indigenous people by white people without consultation (Smith 2012). Research done *on* Indigenous people are those projects that do not reflect the interest of Indigenous people, those that benefit the researcher as opposed to the researched and those projects not done in consultation with Indigenous people (Smith 2012). Often these projects contribute to negative stereotypical viewpoints and disregard Indigenous ways of knowing, being and doing.

Decolonising theory interrogates imperial and colonial power in research and invokes Indigenous knowledge systems (Smith 2012). The theory challenges thinking where Indigenous identity is framed and represented as deficit. It challenges descriptions that have been made of Indigenous identity as being 'not normal'. Decolonising research aims to re-build after the damage caused by colonisation, new knowledge that carries hope for Indigenous people (Smith 2012). In research, '…*decolonization illuminates a ground for powerful presences for it asserts relationality, mutuality and connectivity instead of domination, control and hyper-separation*' (Rose 2004, p. 213). In terms of relationality, engaging a decolonising methodology offers ways to find new and possible relationships as a result of becoming more aware. Mutuality is accounted for by a loss of control with reciprocity. Connectivity speaks to the interdependence of the concepts of responsibility, accountability, proximity, ethics, and community (Rose 2017, p. 494). These are concepts informing the lives of many Indigenous people for millennia (Rose 2017) and are concepts core to this research process.

The use of a decolonising lens in research is very applicable to non-Indigenous researchers such as myself when working in an Indigenous space. The process of a decolonising methodology in research requires culturally acceptable approaches be engaged (NHMRC 2003). This happens when Indigenous people are engaged with collaboratively, where research is informed by Indigenous people and Indigenous people have equal input on how research outcomes are drawn and used (NHMRC 2003). Decolonisation in research gives a voice to Indigenous knowledge (Smith 2012). As the focus of this research is burns care for Aboriginal and Torres Strait Islander children, a decolonising methodology is necessary as I don’t want to replicate the misaligned research done by non-Indigenous researchers in the past.

Interface research methodology to inform this research

‘*In research it is the researcher’s understanding of the world that forms and influences how they enact practice theories*’ (Muller 2014, p. 68). The exploration of theoretical frameworks and research theories thus far has been through my understanding of these concepts. From this exploration I have been able to find those theories that are relevant to me as a non-Indigenous Western biomedically trained, registered nurse. These theories are also fundamental to the conduct of this research to facilitate outcomes that will translate to improved health and healing for Aboriginal and Torres Strait Islander children. For this research to honour and value both systems of knowledge - Aboriginal and Torres Strait Islander and Western biomedical - the knowledge systems need to be brought together in a way that is respectful of and enables each knowledge system to grow. The space were these knowledges need to come together is not a place of contest, rather in a place of collaboration. Durie (2005, 2004) offers a way to do this with interface research methodology. Interface research is a methodology to be engaged with by non-Indigenous people (Durie 2005, 2004). It aims to include non-Indigenous people in a space where notions of dominance and superiority are suspended and where there is mutual respect of knowledges (Durie 2005, 2004). By doing research at the knowledge interface, I am able to come to a place where I can properly take account of the Indigenous research paradigm described. Regardless of my understanding, experience and much interest in healthcare for Aboriginal peoples across South Australia, I will never be able to be in the Indigenous research paradigm. However, I can do research at the interface by acknowledging my Western biomedical standpoint and the validity of the Indigenous paradigm.

To respect both knowledge systems, this research project will support the validity of each system of knowledge and address Durie’s (2004) four principles: *mutual respect, shared benefits, human dignity* and *discovery*. This will be through the *mutual respect* and equitable inclusion of Indigenous and Western research methodologies where empathy will guide respectful research processes. There will be *shared benefits* in the research process and outcomes of the project. Cultural and spiritual beliefs and practices will be reinforced in the research process to maintain *human dignity*. A focus on the *discovery* of new knowledges, through innovation and exploration using Indigenous and Western methodologies will drive the research project. Discovery also relates to the self, and this project will investigate what this means to work at the interface of knowledges as it relates to burns care for Aboriginal and Torres Strait Islander children.

The decolonising approach will bring together the knowledges and take the best of everything we know about burns care from a scientific biomedical model, and the best of everything we know about quality care for Aboriginal and Torres Strait Islander children when they are unwell. These knowledges will come together in a decolonised interface space. Researching in this space and from a decolonising perspective, will mean investigation of burns care in Australia for Aboriginal and Torres Strait Islander children will be in a space that is about transformation and reformation.

Interface research methodology from a decolonising perspective will be engaged to explicitly explore burns care and the presence of the conflict of knowledge that may manifest in the provision of burns care. This is not a matter of one world view over another, rather an opportunity to privilege both knowledges, while bridging the epistemic differences. Interface research methodology provides a space to respect and represent knowledge equally and to create new knowledge. This methodology will provide an opportunity to consider burns care from a critical stance and make new and more relative understandings about care for Aboriginal and Torres Strait Islander children.

Ganma theory

Interface research methodology provides an opportunity for integration and interfacing of Aboriginal and Torres Strait Islanders peoples' knowledge and scientific concepts (Durie 2004, 2005), and can be likened to Ganma (Pyrch & Castillo 2001). Ganma is a theory developed and shared by Yolgnu people of Arnhem Land, Northern Territory, Australia. Ganma describes when fresh and salt water meet and a new environment is created. This is depicted in Figure 1 (Ynggirringa & Garnggulkpuy 2007). Water is a symbol of knowledge in Yolŋu philosophy, and the metaphor of the meeting of two bodies of water is a way of talking about the knowledge system of two cultures working together. Ganma can be a metaphor for the coming together of different knowledges, for the creation of new knowledge. Ganma is a place where knowledge is (re) created (Pyrch & Castillo 2001). This methodology provides opportunities to rebalance the use and application of different knowledges and make new understandings relative to the specifics about burns care for Aboriginal and Torres Strait Islander children and families. As such, Ganma is a theory to facilitate actualisation of interface research methodology.

Figure 1 - Ganma

Image has been removed due to copyright restriction.

I am interested in not just investigating burns care and describing it. I am interested in what can be done to address the health care inequities experienced by Aboriginal children requiring burns care. I cannot redress the root causes of these inequities in a PhD, but I can explore how burns care for Aboriginal and Torres Strait Islander children and families is delivered and what mechanisms inform the delivery of that care. In doing this, I am able to make informed recommendations for improved care. Given Australia’s high-income status and resource rich situation; the wealth of burns care knowledge held by healthcare professionals; access to world class surgical care facilities and specialised medical personnel; and the insurmountable amount of documented evidence of inequities, there must be a way forward. This study does not focus on describing, nor measuring the inequities experienced by Aboriginal and Torres Strait Islander children. Rather, the study recognises there is a need for reform and transformational change and focuses on addressing health inequities as they relate to burns care for Aboriginal and Torres Strait Islander children.

Chapter summary

In health services research issues relating to power imbalances, ownership of knowledge and practice application are important. These issues are heightened when working with children, particularly those who are vulnerable due to the impact of colonisation and through geographic location. In this chapter, I described the epistemological, theoretical and methodological approaches that will inform this research. I began by reviewing the key theories influencing this research. I presented a review of each theory and acknowledged my standpoint in this research. Through this exploration of theories, and given the research is focused on a health inequity experienced by Aboriginal and Torres Strait Islander children who access mainstream services for healthcare, interface research methodology and Ganma theory have been found to be most suitable. Interface research methodology and Ganma theory have been generated by Indigenous people. These two theories aim to include non-Indigenous people in moving forward and as such are relevant to this research and appropriate to me as a non-Indigenous researcher. Aboriginal and Torres Strait Islander and Western knowledges will be interfaced throughout the thesis and in the interpretation of the findings.

SECTION A: SUMMARY

In this section I have positioned myself as a non-Indigenous woman exploring healthcare for Aboriginal and Torres Strait Islander children who have experienced burns. The principal of reflexivity has been described as vital to ensure the legitimacy of the research as a non-Indigenous person. We can see clearly the impact Australia’s history has had on the health outcome inequities experienced by Aboriginal and Torres Strait Islander children and how these inequities are compounded by issues of access to Australia’s mainstreams healthcare system. I have identified interface research methodology as the theoretical framework that will inform the research as it provides a space to acknowledge, consider and respect both Western biomedical knowledge and the ways of knowing of Aboriginal and Torres Strait Islander peoples. In the following section, I present data about burns injury and the current situation of burns care, especially as it relates to Aboriginal and Torres Strait Islander children.

SECTION B: A DISCONNECT IN BURNS CARE

In this section I present an overview of burns injury, especially as it relates to burns experienced by Aboriginal and Torres Strait Islander children. I then present information about burns care, and discuss Australia's healthcare system at large from which burns care is delivered. In doing so, I introduce issues concerning burns care for Aboriginal and Torres Strait Islander children in Australia.

In the fifth and sixth chapters I embed the findings of two published literature reviews. The first is investigating telehealth as it relates to care of Indigenous peoples with chronic conditions. The second is investigating quality and cultural safety in burns injury models of care. Investigation of how cultural competency can be embedded in telehealth and how existing models of care inform burns care, along with how it is structured and delivered in Australia, especially for care of Aboriginal and Torres Strait Islander children and families contributes to the current body of evidence. Despite the limited research evidence specifically relating to Aboriginal and Torres Strait Islander children and burns care, both systematic reviews highlight specific gaps in the research evidence requiring further investigation.

During my higher degree research candidature, I was also contracted to complete the search, assessment and synthesis of literature for a review of access to burns care rehabilitation in low and middle income (LMIC) countries. This review has since been published in *Burns* and can be seen in Appendix 2. Some of the health inequities experienced by Aboriginal and Torres Strait Islander peoples, including those regarding access to care are similar to those experienced by people in LMIC countries. Especially those related to the social determinants of health. The review identified many barriers to the provision of high quality and accessible burns rehabilitation services. These included such things as language barriers and geographical isolation. These barriers are similarly experienced by Aboriginal and Torres Strait Islander children and families. This review about burns care rehabilitation in LMIC found that in order to inform policy and service delivery in LMIC countries, current provision of burns rehabilitation needs to be investigated. This review contributed to the findings of the above-mentioned reviews about telehealth and models of care and further highlights the need for a thorough investigation into burns care in the Australian setting. As a result, my involvement in, and the inclusion of this research in the thesis is appropriate.

CHAPTER 3 – Inequities in burns injury and current burns care

In this chapter I provide a summary of burns injury and burns care, with a focus on the current Australian situation and healthcare system. I present data regarding the incidence of burns injury and current trends of hospitalisation; making clear the health outcome inequity experienced by Aboriginal and Torres Strait Islander children. I then introduce the current practice of burns care; including the guidance to burns care, consideration of Australia's healthcare system and care of Aboriginal and Torres Strait Islander children within that system.

Burns injury

The WHO (2018) describes a burn as an injury to the skin primarily caused by thermal trauma. A burn occurs when some of the cells in the skin are destroyed by scalds, contact or flames. Injuries to the skin due to radiation, electricity, friction or contact with chemicals are also identified as burns. Burns injuries, a public health issue of high economic importance, continues to be a major problem both in developed and developing countries, affecting mostly children and the elderly (Forjuoh 2006, Peck, Kruger, Van Der Merwe et al. 2008, Okoro, Igwe & Ukachukwu 2009, WHO 2018). In 2018, the WHO (2018) reported an estimated 180,000 deaths every year are caused by burns, with millions more causing severe and permanent disability. A global review of child burns injuries and relative country economics found that in 2013 the mortality rate for children aged 1-14 was 2.5 per 100,000 (Sengoelge, El-Khatib & Laflamme 2017). The burden was highest in low and middle income countries (LMIC).

The epidemiology of burns injury is similar across the world. Children are affected by burns injury more than adults, especially those between the ages of one and four and males are more likely than females to suffer a burns injury across all ages (WHO 2018). These statistics are reported differently in a systematic review of burns epidemiology in LMIC, whereby older females are equally at risk of burns injuries as young males (Rybarczyk, Schafer, Elm et al. 2017). In the UK, males accounted for 63% of patients cared for in specialised burns injury services (Stylianou, Buchan & Dunn 2015) and the most frequent cause of burns injury was for scalds(Stylianou, Buchan & Dunn 2015). There is a higher incidence of burns injury in LMIC than in developed countries, and people of low socioeconomic status around the world suffer burns injuries at substantially higher rates than people with higher socioeconomic status (WHO 2018).

A recent systematic review of research investigating current burns epidemiology showed the incidence of burns injury and severity, rates of hospitalisation and lengths of stay, and rates of mortality are decreasing around the world (Smolle, Cambiaso-Daniel, Forbes et al. 2017). However, while mortality rates have been decreasing, there has been a rise in mortality attributable to past burns injury later in life (Duke, Rea, Boyd et al. 2015). This highlights the importance of access to ongoing healthcare to minimise burns-related complications and maximise recovery and quality of life.

Burns injuries in Australia and resultant hospitalisation

In Australia between 2000-2006, one quarter of patients hospitalised for burns were found to have hospital stays of at least one week (Wasiak, Spinks, Ashby et al. 2009). Between 2009-2010, 13.3% of all hospitalised cases for exposure to smoke, fire, heat and hot substances had a high threat to life and the mean length of stay was 5.2 days (Tovell, McKenna, Bradley et al. 2012). A more recent report by the Burns Registry of Australia and New Zealand (BRANZ) using data over a 12 month period in 2015-2016 identified the median length of stay for paediatric patients was four (2-8) days, and five (3-11) days for adults (BRANZ 2015). These rates of hospitalisation and associated length satay are indicative of the serious nature of burns injury.

The AIHW reported in 2009-2010 that there were 2220 children hospitalised for burns injuries across Australia (Tovell et al. 2012). For the period 2013-2014, the AIHW (2016b) reported that 1409 children aged 0-14 years in Australia were hospitalised following burns injury. The highest rate of burns injury in this group was in the youngest age range (0–4) for both boys and girls. For boys, there were 75 cases per 100,000 population, and for girls, there were 51 cases per 100,000 population. Contact with heat and hot substances caused the majority of these burns. For all ages, the age-standardised rate of hospitalised burns cases increased in line with increasing remoteness, from 18 cases per 100,000 for residents of major cities to 102 cases per 100,000 for very remote residents (AIHW 2016b). A retrospective review of 10 years of data from 2001 to 2012 identified the annual cost of hospitalisation for child injury in Australia was $A212 million (Mitchell, Curtis & Foster 2018). A government report estimated that between 2006-2007, the cost of acute inpatient burns care was $65 million (Australia Parliament House of Representatives 2010).

The experiences of burns injuries by Aboriginal and Torres Strait Islander peoples

The AIHW (2016b) reported a total of 480 hospitalised burns cases were recorded for Aboriginal and Torres Strait Islander people in 2013–2014. These accounted for 9% overall of all hospitalised burns cases. The age-standardised rate for those hospitalised burns injuries in Aboriginal and Torres Strait Islander peoples was 58 cases per 100,000 population compared to 22 cases per 100,000 for other Australians. The AIHW (2016b) also reported Aboriginal and Torres Strait Islander children (0 to 14 years) are hospitalised for burns injury almost twice as often as for non-Indigenous children. For Aboriginal and Torres Strait Islander children, the largest proportion of hospitalised burns cases was in the youngest age group (0-4 years) for both males (30%) and females (31%) (AIHW 2016b). These figures reflect those collected by the Australian and New Zealand Burns Association who reported of the patients admitted to burns units in Australia in 2013–2014, 11% of paediatric patients identified as Aboriginal or Torres Strait Islander (De Silva, Gabbe, Callaghan et al. 2014). In regard to geography, the rate of burns injury per 100,000 population by area of residence is substantially higher for Aboriginal and Torres Strait Islander people than for the rest of the population: 75.5 compared to 62.1 in very remote areas and 16.8 compared to 6.9 in urban areas (Cameron, Gabbe, Watterson et al. 2011).

The AIHW (2010a) report significant evidence for the importance of collecting Indigenous status in health-related data. Poor collection of this data results in under-identification and is reported in many reports across different health domains. This is the case for identification on admission into a tertiary health service (Productivity Commission 2015). Documented measures on how to collect this data (AIHW 2010a) and on improving identification rates exist (ACSQHC 2017b). Furthermore, data collected on outpatient burns care is not routinely collected or analysed. As a result there is difficulty in ascertaining the exact burden of burns in Aboriginal and Torres Strait Islander children and may result in under-reporting of burns injuries in this population. Regardless of the limits of the data, it is clear that in Australia, Aboriginal and Torres Strait Islander children experience burns injury at disproportionally higher rates than non-Indigenous children. This is one of many health inequities experienced by this population of children.

Outcomes following a burns injury

While it is clear that a health inequity exists, there is very little research evidence relating to outcomes following a burns injury that investigates differences between Aboriginal and Torres Strait Islander and non-Indigenous children. International studies show that poorer health and functional outcomes are linked to lower socioeconomic status following some childhood injuries (Prasad, Ewing-Cobbs, Swank et al. 2002, Schwartz, Taylor, Drotar et al. 2003, Anderson, Morse, Catroppa et al. 2004, Yeates, Swift, Taylor et al. 2004, Polinder, Meerding, Toet et al. 2005, Anderson, Catroppa, Dudgeon et al. 2006, McCarthy, MacKenzie, Durbin et al. 2006). Sheridan, Hinson, Liang et al. (2000) showed that for children in the United States surviving very large burns, better outcomes were realised with consistent follow-up care, recommencement of activities engaged in prior to the burns injury, and functionality of family unit. This is supported by a subsequent study that showed recovery from a burns injury is influenced by family characteristics (Sheridan, Lee, Kazis et al. 2012). In Australia, there is evidence that outcomes following a burns injury are far reaching and that a burns in childhood can result in poorer school outcomes (Azzam, Oei, Adams et al. 2018). A large population-based cohort analysis of linked hospital and mortality data for 2000–2014 showed Aboriginal and Torres Strait Islander children experience larger burns than non-Indigenous children and stay in hospital for longer. The mean length of stay was almost three days longer (6.1 days versus 3.4 days). This was the case after adjusting for burns characteristics and home geography (Möller et al. 2017). It is not completely clear how or if follow-up care for Aboriginal and Torres Strait Islander children is accessed. Nor is it clear how socioeconomic status, family functionality or being Aboriginal impacts health-related outcomes following a burns injury for Aboriginal and Torres Strait Islander children.

Burns care

The serious nature of burns injuries necessitates specialist care delivered in dedicated facilities by experts in burns care (Al-Mousawi, Mecott-Rivera, Jeschke et al. 2009). These specialist burns services provide access to intensive care support and surgical intervention (American Burn Association 2017). Burns care is also best delivered by a team of multidisciplinary healthcare professions who facilitate care across a continuum from injury through to rehabilitation (Al-Mousawi et al. 2009, D'cruz, Martin & Holland 2013). Burns care spans from acute to chronic management and can sometimes be required over extended periods of time (Al-Mousawi et al. 2009, D'cruz, Martin & Holland 2013).

Australia is a large country, separated into eight main jurisdictions known as states or territories. These include South Australia, Western Australia, Queensland, New South Wales, Australian Capital Territory, Northern Territory, Victoria and Tasmania. The geography and vastness of Australia’s land challenges the delivery of healthcare (AIHW 2018). In addition, population spread and subsequent tertiary healthcare placement, sometimes makes accessing face-to-face specialist care difficult. To address issues of geography, including those related to economics, the use of telehealth for burns care has becoming increasingly popular (Smith, Kimble, O'brien et al. 2007, McWilliams, Hendricks, Twigg et al. 2016). There are five dedicated paediatric burns units situated within metropolitan paediatric tertiary health services across Australia. Other burns units exist in both adult services and in services who treat both adults and children.

Burns treatment in Australia varies across jurisdictions and between healthcare facilities. Follow-up care for scar management may involve repeat visits to the tertiary burns unit (particularly with serious burns) or patients may be required to travel to their closest regional health service for care and/or telemedicine consultations. In Western Australia, the use of telehealth for paediatric burns care has increased since its introduction in 2005 (Al-Mousawi et al. 2009, McWilliams et al. 2016). This is reported similarly in Queensland (Smith et al. 2007). In New South Wales, children from regional or remote areas are more likely to be admitted to hospital and stay for longer than children from metropolitan areas. These children are discharged earlier with the perceived ability to access out-patient care easier than those from regional or remote areas (Hyland, Zeni, Harvey et al. 2015). Decisions such as these may be pragmatic and associated with distance and travel. In some remote jurisdictions, allied healthcare professionals visit remote communities and are able to provide follow-up care. Relative to all burns injured patients and across all jurisdictions, much evidence exists for the use of very necessary surgical intervention and wound management.

In Australia models of care also exist to guide burns teams in the delivery of burns care (Government of Western Australia 2009, ACI 2011, Government of South Australia 2014). These are jurisdictionally based. Various associations, such as the Australian and New Zealand Burns Association (ANZBA), quality improvement agencies such as the Agency for Clinical Innovation and research institutes such as The Joanna Briggs Institute, develop protocols for burns care and best practice guidelines. Inherent internal documents also guide the delivery of care in tertiary health service sites. There is little written evidence about if, or how, any of these documents inform burns care for children in Australia.

The structure of Australia's health system also shapes how individuals access very necessary burns care. This includes such things as access to tertiary care and receiving healthcare via telehealth. Given the disproportionate number of Aboriginal and Torres Strait Islander peoples living in remote locations, it follows that telehealth, a contemporary alternative to accessing face-to-face care, is also accessed disproportionately. It is not clear if, or how, telehealth is congruent with Aboriginal and Torres Strait Islander peoples' constructs of health and healing.

There have been dramatic advances in the use of telemedicine worldwide, aiming to facilitate high quality care without having direct physical access. This is also the case in Australia. The complexity of burns treatment and subsequent specialist care required, along with the need for access to sustained follow-up care for serious burns, provided a stimulus for telehealth to be considered for burns care (Smith, Youngberry, Mill et al. 2004). However, the evidence for the use of telehealth and its ultimate role and effectiveness in providing healthcare to Indigenous peoples requiring healthcare over extended periods are yet to be clearly defined. Further still, there is very limited published research examining its acceptability as a treatment modality for Aboriginal and Torres Strait Islander families, specifically as it relates to burns care. Subsequently there is a need for more research in order to ensure it is appropriately implemented (Wallace, Hussain, Khan et al. 2012). In chapter four I present a published systematic review of the use of telehealth as a modality for healthcare with Indigenous peoples. The review critiques existing research evidence regarding the effectiveness, acceptability and feasibility of the use of telehealth with Indigenous peoples requiring healthcare for chronic conditions.

Very little research evidence exists about burns care for Aboriginal and Torres Strait Islander peoples. Given the differences between the Western biomedical model of healthcare and Aboriginal and Torres Strait Islander peoples' constructs of health and healing, this is of significant concern. Furthermore, it is not clear if, or how, the documents (Government of Western Australia

2009, ACI 2011, Government of South Australia 2014) that inform burns care provide appropriate guidance for the provision of care for Aboriginal and Torres Strait Islander children.

Chapter summary

In this chapter I have described the serious nature of burns injuries and burns outcomes, especially as they relate to Aboriginal and Torres Strait Islander children. In some instance, for example length of stay, there are difference in care outcomes for Aboriginal and Torres Strait Islander children. Following this, the structure and delivery of the care of burns in Australia was presented, concluding that there is no clarity about how the system meets the needs of Aboriginal and Torres Strait Islander children and families. To explore these issues, I undertook a critique of telehealth as a modality to the provision of care for Indigenous peoples with a chronic condition. This is presented in chapter four. This is followed by a critique of existing publicly available burns injury models of care in chapter five. These resources were critiqued for quality and cultural safety providing an exploration of the current context in Australia for care of Aboriginal and Torres Strait Islander children.

CHAPTER 4 – Use of telehealth for health care of Indigenous peoples with chronic conditions: a systematic review

Throughout the world, ‘telehealth’ is being adopted as an approach to the delivery of health care. This is especially the case when considering the provision of health care to people residing in geographically difficult to reach places. Using telehealth as a means to facilitate health care for those people with a chronic condition, for frequent and sustained care requirements, may improve efficiencies. As treatment for a burns injury can mean care is required over extended periods, telehealth may prove effective. It is not clear if telehealth is an appropriate model of care for the care of Indigenous peoples. This chapter presents a review of the use of telehealth for health care with Indigenous peoples suffering a chronic condition. The term Indigenous is used throughout this paper to represent Indigenous people from around the world. The original work presented in this chapter has been published in the peer-reviewed literature.

Citation

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Attribution of Authorship

Authors SF (80%), TM, JG, KH, RI all contributed to the conception and design of this systematic review. Data collection was completed by SF (100%). Analysis and interpretation of research data was performed by SF (80%) and contributed to by authors TM, JG, KH, KT and RI. Drafting of the manuscript was completed by SF (90%), and revision of significant parts of the work so as to contribute to the interpretation was contributed to by SF, TM, JG, KH, KT and RI.

Introduction

Chronic diseases including such conditions as cardiovascular, respiratory and renal diseases, as well as disability caused by injury such as burns and spinal cord injury, affect many people around the world. These conditions are mostly characterised by complex causality, multiple risk factors, long latency periods, a prolonged course of illness and functional impairment or disability (AIHW 2010c). As a result of their often intense and prolonged requirement for health care, chronic conditions impose significant costs and challenges to health systems aiming to deliver cost effective, yet effective and appropriate healthcare (WHO 2014). Compounding these challenges is the fact that chronic conditions disproportionally affect more Indigenous than non-Indigenous people, for whom it has been shown have significant challenges accessing healthcare (Di Cesare, Khang, Asaria et al. 2013, AIHW 2014).

Telehealth, a relatively new modality for healthcare delivery, aims to address some of the challenges facing health systems by increasing healthcare access and quality, enhancing health outcomes and reducing the high costs associated with speciality healthcare services (Craig & Petterson 2005, Heinzelmann, Lugn & Kvedar 2005). Telehealth is currently used differently across the world with various levels of effectiveness for healthcare administration, provision and education (WHO 2010a). There are no strict definitions for telehealth: in some instances, telehealth is described as a model of care when distance separates those involved (AIHW 2014). At other times, it is recommended as a modality used to strengthen the provision of healthcare (WHO 2010a). Broadly speaking, telehealth is the use of information and computer technologies to deliver healthcare and transmit health information (AIHW 2014).

Telehealth lends itself to providing some of the necessary ongoing healthcare for people suffering chronic conditions (Smith et al. 2004, McWilliams, Gilroy & Wood 2007, Polisena, Tran, Cimon et al. 2009, Polisena, Tran, Cimon et al. 2010), and as a result, may have a positive influence on the health and wellbeing of Indigenous peoples experiencing inequitable access to healthcare. This is particularly the case where people experience geographical isolation and system factors that can inhibit access. The evidence for telehealth is still developing, and the cost effectiveness of telehealth is inconclusive due to lack of quality research data (Mistry 2012, De La Torre-Díez, López-Coronado, Vaca et al. 2015).

Health care provided using telehealth to Indigenous peoples often occurs at the cultural interface between non-Indigenous healthcare professional and Indigenous patient. The cultural interface is where different knowledge systems interact: '*it is a place of tension that requires constant negotiation*' (Nakata 2002, p. 19). Telehealth, a subsidiary of technology, cannot be separated from the actual health care itself. Like any health care provision for Indigenous peoples, telehealth needs to be culturally appropriate for it to have meaningful health benefits (Waldram, Herring & Young 2006). A recent report highlighted how the introduction of culturally specific care '*…through culturally knowledgeable providers, onsite tribal outreach workers…as well as building rapport, trust, and engagement with the target patient population*' (Shore, Kaufmann, Brooks et al. 2012 p. 87-94) may support more culturally safe care. However, there are gaps in the published research regarding how well telehealth can deliver culturally appropriate care to Indigenous peoples (Maar, Seymour, Sanderson et al. 2010).

Telehealth reviews highlight the need for further exploration around the acceptability of telehealth for use with Indigenous peoples (Durkin 2008, Thompson, Shelton, Mitchell et al. 2013). Where telehealth is received favourably, it is not clear if this is about telehealth per se or about the benefits of receiving any service at all in a remote community (Richardson, Christopher Frueh, Grubaugh et al. 2009). More consideration of the effectiveness of telehealth in terms of providing culturally appropriate health care to encompass a more holistic concept of health for Indigenous peoples would be helpful in providing a clear understanding. Critical reflection of all telehealth processes and reported outcomes, including from the perspective of the Indigenous peoples who use the service, would be valuable.

Reflection of telehealth in alignment with Indigenous ways of being, doing and knowing to meet the needs of Indigenous peoples is justified. Helen Milroy’s contemporary Aboriginal model of holistic health includes cultural, spiritual, social, emotional and physical dimensions (Australian Indigenous Doctors’ Association 2010). Influenced by historical, traditional and contemporary layers, Milroy emphasises ‘*the intersection of both the layers and dimensions which creates the interconnectedness for a whole of life approach to Aboriginal wellbeing’* (Australian Indigenous Doctors’ Association 2010). As a result, health systems that produce models of care that include telehealth, and the healthcare professionals enacting health care via telehealth, should incorporate and support a holistic view of health such as this. Further still, to be acceptable for recipients, telehealth as a modality for health care provision for Indigenous peoples needs to be culturally safe. Culturally safe care is an outcome defined only by the individual receiving care (Papps & Ramsden 1996), and is usually experienced by those who receive care from culturally competent healthcare professionals and systems (Durie 2001).

This review is a systematic meta-synthesis to describe the effectiveness of telehealth for the care of Indigenous peoples with chronic conditions. The focus is to critique the evidence of telehealth for managing chronic conditions in Indigenous populations in three ways: the effectiveness of telehealth in terms of health outcomes (morbidity, mortality and quality of life); the acceptability of telehealth as to how it encompasses a holistic model of health for Indigenous peoples as healthcare consumers and for healthcare professionals; and the feasibility of uptake for health services. Information and communication technologies have the unique capacity to reach underserved populations because of their wide and instant dissemination capability. The evidence for the implementation of telehealth and its ultimate role and effectiveness in providing health care to Indigenous peoples requiring chronic conditions management are yet to be clearly defined. This is especially the case for respecting non-Western biomedical views of health and wellbeing and the lack of evidence for the use of telehealth in respecting the cultural values and health beliefs of Indigenous peoples. It is unclear if actual health outcomes and inequities can be addressed for Indigenous peoples through the uptake and use of telehealth in health services.

Methods

Search Strategy

A systematic search of the literature was conducted in August 2015 for studies relating to three concept areas: telehealth; Indigenous status; and chronic conditions. Studies were identified from an electronic database search using a combination of subject headings and keywords (Appendix 3) in the following databases: MEDLINE and MEDLINE in Process; CINAHL; Web of Science; SCOPUS; Informit; and the Cochrane Library. The search included the following limitations: English language; and last ten years.

Inclusion and exclusion criteria and quality appraisal

Studies were included in this review if they met each of the following criteria: presented findings from primary research; investigated any aspect of telehealth supporting chronic conditions management; involved Indigenous peoples of any age; and addressed one of the three research questions. Qualitative and quantitative studies were included and all case series and reviews excluded. For each of the three research question (effectiveness, acceptability and feasibility), a range of outcomes were eligible. Outcomes for effectiveness related to Indigenous peoples' health outcomes. Evidence of acceptability were by perception of telehealth use by Indigenous peoples as healthcare consumers in terms of cultural acceptability and healthcare professionals in terms of health service delivery. Outcomes related to feasibility were directly regarding health service impact, for example diagnostic capabilities.

The included studies were summarised using a standard data extraction form including a combination of the following items dependent on study type: aim; study design; participants; Indigenous group; Country; telehealth intervention; chronic condition management; outcome; and study limitations. Where identified, facilitators and barriers to telehealth as a modality in healthcare delivery were also recorded. The strength of evidence for each of the studies included for review was assessed using criteria from the Joanna Briggs Institute (2001, 2013). Levels of Evidence for Effectiveness in Table 1 (The Joanna Briggs Institute 2001) and Grades of Recommendation in Table 2 (The Joanna Briggs Institute 2013) were assessed for all included studies.

Synthesis

Data selected for inclusion were narratively synthesised and initially presented in terms of quality and design for each research question. The effectiveness of telehealth in terms of health outcomes of consumers were grouped thematically by intervention type, origin of research and health outcome. The acceptability of telehealth data were presented narratively; firstly for consumers and secondly healthcare professionals. Data relating to feasibility of telehealth were synthesised in terms of health service impact.

Table 1 - Levels of Evidence for Effectiveness

Level 1	Experimental Designs
Level 1.a	Systematic review of Randomised Controlled Trials (RCTs)
Level 1.b	Systematic review of RCTs and other study designs
Level 1.c	RCT
Level 1.d	Pseudo-RCTs
Level 2	Quasi-experimental Designs
Level 2.a	Systematic review of quasi-experimental studies
Level 2.b	Systematic review of quasi-experimental and other lower study designs
Level 2.c	Quasi-experimental prospectively controlled study
Level 2.d	Pre-test – post-test or historic/retrospective control group study
Level 3	Observational – Analytic Designs
Level 3.a	Systematic review of comparable cohort studies
Level 3.b	Systematic review of comparable cohort and other lower study designs
Level 3.c	Cohort study with control group
Level 3.d	Case – controlled study
Level 3.e	Observational study without a control group
Level 4 –	Observational – Descriptive Studies
Level 4.a	Systematic review of descriptive studies
Level 4.b	Cross-sectional study
Level 4.c	Case series
Level 4.d	Case study
Level 5	Expert Opinion and Bench Research
Level 5.a	Systematic review of expert opinion
Level 5.b	Expert consensus
Level 5.c	Bench research/single expert opinion

Table 2 - Grades of Recommendation

Grade A	A ‘strong’ recommendation for a certain health management strategy where (1) it is clear that desirable effects outweigh undesirable effects of the strategy; (2) where there is evidence of adequate quality supporting its use; (3) there is a benefit or no impact on resource use, and (4) values, preferences and the patient experience have been taken into account.
Grade B	A ‘weak’ recommendation for a certain health management strategy where (1) desirable effects appear to outweigh undesirable effects of the strategy, although this is not as clear; (2) where there is evidence supporting its use, although this may not be of high quality; (3) there is a benefit, no impact or minimal impact on resource use, and (4) values, preferences and the patient experience may or may not have been taken into account.

Results

The electronic database search returned 2680 studies. Of these studies, 1863 duplicates were removed, leaving 817 studies for screening of title and abstract. A further 713 studies were excluded in this process, resulting in 104 studies being assessed in their entirety for inclusion in this study. From this analysis, 32 met the inclusion criteria for the review. The study selection process is summarised in the PRISMA flow chart. Included studies were grouped according to main stated aim. Studies with two or more main aims appear across groups. Of the 32 studies included in this review: 11 examine the effectiveness of telehealth in regards to health outcomes for Indigenous people (Appendix 4); 10 critique the acceptability of telehealth by Indigenous peoples as healthcare consumers (Appendix 5) and eight report the acceptability of telehealth from the perspectives of healthcare professionals (Appendix 6); and 12 examine the feasibility of telehealth for health services (Appendix 7).

The telehealth modalities described in the studies were mostly real-time video-conferencing, internet based applications and portals, and asynchronous technologies. The term telehealth, used collectively throughout this paper, was referred to differently in the included studies and synonymous with: teleoncology; telemedicine; teleopthalmology; computerised therapy; web-based therapy; and telemental health. For the included studies, the Indigenous peoples of the countries Australia, Northern America, Canada, New Zealand and the Pacific Islands are referred to as Aboriginal and Torres Strait Islander, First Nations, American Indian, Alaska Native, Hawai'ian, Maori and Islanders respectively. The term Indigenous peoples is used throughout where results and discussions are collective. A small number of the studies were not entirely dedicated to Indigenous peoples and had a proportion of non-Indigenous study participants. Chronic conditions described in the included studies were: cancer; congestive heart failure; chronic obstructive pulmonary disease; type 2 diabetes; mental health conditions; otitis media; heart failure; diabetic retinopathy and injury. The term chronic condition is used throughout where results and discussions are collective. Telehealth was used to manage the chronic conditions of Indigenous peoples through referral, assessment, review, monitoring, support provisions, medication management and self-management.

The published studies suggested that telehealth is being used in various ways across the world for chronic condition management with Indigenous populations. The studies also suggested telehealth can be at least as good as face-to-face clinical care assessment, and may improve access to care. Unfortunately, as there were no comparative published studies on health outcomes it is difficult to prove equality or superiority. The studies reported Indigenous people tend to be satisfied with the use of telehealth (Doorenbos, Eaton, Haozous et al. 2010, Jernigan & Lorig 2011, Pruthi, Stange, Malagrino Jr et al. 2013) particularly as it can address the barriers associated with living remotely and away from specialised care (Reeve, Thomas, Mossenson et al. 2014). However some studies reported Indigenous people having reservations about the information and communication technologies including concerns about privacy and confidentiality (Mooi, Whop, Valery et al. 2012) and feeling general discomfort (Shore, Brooks, Savin et al. 2008). For the studies reported by health services, telehealth was feasible in terms of health care and service delivery, and healthcare professionals were somewhat satisfied with using telehealth, however found difficulties with information and communication technologies a consistent barrier. The data and heterogeneity of the 32 included studies meant they were not suitable for meta-analysis, and as such a meta-synthesis is used to report in narrative form.

1. **Effectiveness of telehealth** (Appendix 4)

Of the 32 studies described in this review, 11 reported the effectiveness of telehealth in terms of health outcomes (morbidity, mortality and quality of life (QOL)) for Indigenous peoples requiring chronic condition management. Study types included four RCTs (Lorig, Ritter, Laurent et al. 2010, Venter, Burns, Hefford et al. 2012, Mansberger, Gleitsmann, Gardiner et al. 2013, Mansberger, Sheppler, Barker et al. 2015), four pre/post (Buckley & Weisser 2012, Shore, Brooks, Anderson et al. 2012, Fredericks, Clark, Adams et al. 2013, Reeve et al. 2014), two comparative (Robertson, Kattelmann & Ren 2007, Riley, Keberlein, Sorenson et al. 2015) and one prospective (Turner, Robinson, Tian et al. 2013). Whilst the results indicated that telehealth may improve morbidity and QOL and reduce mortality, studies were limited by factors such as small sample size (Robertson, Kattelmann & Ren 2007, Venter et al. 2012, Fredericks et al. 2013, Turner et al. 2013), short surveillance periods (Mansberger et al. 2013), retrospective data (Buckley & Weisser 2012, Shore et al. 2012, Reeve et al. 2014), lack of controls (Buckley & Weisser 2012, Shore et al. 2012, Turner et al. 2013, Reeve et al. 2014) and lack of randomisation (Robertson, Kattelmann & Ren 2007, Buckley & Weisser 2012, Shore et al. 2012, Turner et al. 2013, Riley et al. 2015). The larger RCT with a five year follow up found telemedicine increased the percentage of participants who obtained diabetic retinopathy screening examinations when compared with traditional surveillance. This result may be limited by use of a monetary incentive increasing follow-ups in both groups in the last year of follow-up, however should not have affected the proportional difference (Mansberger et al. 2015).

The most common telehealth intervention, described in six of the studies, was home internet-based monitoring (Robertson, Kattelmann & Ren 2007, Lorig et al. 2010, Venter et al. 2012, Fredericks et al. 2013, Riley et al. 2015). Other telehealth interventions were three asynchronous image/data transfer for screening, diagnosis and monitoring (Mansberger et al. 2013, Reeve et al. 2014, Mansberger et al. 2015) and two evaluating the use of real-time assessment and management of chronic conditions (Buckley & Weisser 2012, Shore et al. 2012). Seven of the studies were based in the USA with American Indian and Alaska Native people, three in Australia with Australian Aboriginal and/or Torres Strait Islander people and one with Maori people from New Zealand. Not all of the participants included in four of the studies were Indigenous peoples (Buckley & Weisser 2012, Mansberger et al. 2013, Mansberger et al. 2015, Riley et al. 2015). Improvements in morbidity were seen by better disease control (Robertson, Kattelmann & Ren 2007, Turner et al. 2013) and reduced hospitalisation rates and days spent in hospital (Shore, Bloom, Manson et al. 2008, Riley et al. 2015). Reductions in rates were not significantly greater when compared with a matched cohort, however changes to services may have contributed to results evident in control group for this study (Riley et al. 2015). Improvements in QOL were evident by a reduction of unnecessary transfers (Buckley & Weisser 2012), increased prescription drug use (Shore et al. 2012) and reduced specialist review wait times (Reeve et al. 2014). In terms of mortality, a substantial but non-significant trend toward reduced mortality in the intervention group of a 12 month pilot study was evident in one of the RCTs limited by a small sample size (Venter et al. 2012).

2. <u>Acceptability of telehealth by Indigenous peoples</u> (Appendix 5)

Of the 32 studies included in this review, 10 reported on the acceptability of telehealth as a modality to health care delivery from the perspective of the Indigenous client. Two of these studies (Mooi et al. 2012, Hiratsuka, Delafield, Starks et al. 2013) looked at both the Indigenous clients' and the healthcare professionals' perspectives. Differentiation between the two perspectives was clear and enabled separate reporting. All studies reported varying degrees of mostly positive acceptance for a variety of telehealth approaches as the modality for delivery of healthcare to manage chronic conditions. In particular, Indigenous people liked reduced travel costs(Hiratsuka et al. 2013). Level of acceptance was obtained predominantly through qualitative interviews (Gibson, Coulson, Miles et al. 2011, Jernigan & Lorig 2011, Fleming, Dixon & Merry 2012, Venter et al. 2012, Arora, Kurji & Tennant 2013, Hiratsuka et al. 2013), and measured by self-reported Likert scales in four studies (Shore et al. 2008, Doorenbos et al. 2010, Mooi et al. 2012, Pruthi et al. 2013). All studies, including two pilot trials (Jernigan & Lorig 2011, Venter et al. 2012), reported via descriptive study design, and were limited by small sample sizes and thus capacity to generalise.

Facilitators to acceptance of telehealth revolved mostly around healthcare professional cultural competence and information and communication technologies capability. Indigenous clients described preferring face-to-face contact (Lorig et al. 2010) because of loss of connection and relationship with the healthcare professional (Hiratsuka et al. 2013). An initial face-to-face meeting was thought to facilitate acceptance of telehealth (Hiratsuka et al. 2013), especially for mental health assessments (Gibson et al. 2011). Client–healthcare professional relationships, linked strongly to trust and rapport, were a reoccurring theme across these studies. In one study examining the use of real-time video-conferencing for management of Type Two Diabetes Mellitus (T2DM), a downfall of telehealth was described by its inability to enable good relationships (Hiratsuka et al. 2013). Furthermore a study that explored acceptability of telehealth for mental health management using real-time video-conferencing highlighted a lack of culturally competent healthcare professionals and systems as key deterrents for the use of telehealth (Gibson et al. 2011). Conversely, some participants reported greater continuity and access to mental health services, reduced travel time, and increased comfort in disclosure through telehealth (Fleming, Dixon & Merry 2012). Similarly, for a small study based in New Zealand (Fleming, Dixon & Merry 2012), young Indigenous people thought favourably of telehealth being the modality to deliver CBT therapy for depression.

3. **Acceptability of telehealth by healthcare professionals** (Appendix 6)

Of the 32 studies included in this review, eight reported on the perspectives of healthcare professionals in terms of their acceptance of using telehealth. Video-conferencing at health services was the telehealth medium described in all but one of the studies (Kim & Driver 2015). Five of these studies also reported on Indigenous client acceptance and health service feasibility and therefore appear in other result sections. Studies reported via qualitative design, typically thematically analysed data presented in narrative form, along with survey data from quantitative studies. All studies reported mostly positive views of telehealth as a modality for the delivery of chronic condition management. Acceptance of telehealth appeared to be facilitated by two main themes. Firstly, knowledge of and reliable information and communication technologies, and secondly, addressing specific cultural factors including Indigenous healthcare professionals and using traditional practices. Reported acceptance was based upon different aspects of care provision, for example good quality care (Pruthi et al. 2013), time-saving (Hiratsuka et al. 2013) and enhanced collaborative care (Mooi et al. 2012). Perceived usefulness of telehealth influenced a healthcare professionals' intention to use the modality (Monthuy-Blanc, Bouchard, Maïano et al. 2013) and resistance to information and communication technologies created a barrier for its uptake (Mooi et al. 2012). Although reporting overall positive satisfaction, a small study (Monthuy-Blanc et al. 2013) based in Canada that surveyed (Brooks, Manson, Bair et al. 2012) healthcare professionals and interviewed five, found that real-time video-conferencing was not appropriate for specific mental health conditions and limited the ability of healthcare professionals to intervene. For these eight studies, surveys were primarily used to gauge the level of acceptance and were limited by small and non-representative samples (Brooks et al. 2012, Haozous, Doorenbos, Demiris et al. 2012, Mooi et al. 2012, Hiratsuka et al. 2013, Pruthi et al. 2013, Kim & Driver 2015) and little or absent descriptions of methods (Brooks et al. 2012, Pruthi et al. 2013).

4. **Health service feasibility** (Appendix 7)

Of the 32 studies included in this review, 20 evaluated various aspects of the feasibility of telehealth use by health services. For the 12 studies that evaluated feasibility in terms of accuracy and service delivery, a range of telehealth methods, interventions and chronic conditions were covered. Five of these studies also assessed acceptability of telehealth for chronic disease management by Indigenous clients and healthcare professionals and are included in other result sections. Feasibility of telehealth for health services was in terms of service delivery and use, healthcare professional outcomes and clinical reliability. Study design, aim and limitations of these 12 studies varied considerably, yet results were relatively consistent. That is, telehealth is feasible for use in the delivery of health care. The studies were a mixture of descriptive, comparative and interventional studies, and included three pilot trials. Whilst not from experimental data, the descriptive studies consistently looked at ways that health services were impacted by the use of telehealth as a modality to healthcare delivery. Results indicated improvements in client involvement with health services (Levine, Turner, Robinson et al. 2009, Elliott, Smith, Bensink et al. 2010, Robinson, Turner, Levine et al. 2011, Kim & Driver 2015). Similarly, healthcare professionals showed positive responses in terms of productivity from the use of asynchronous technology (Kim & Driver 2015) and healthcare competence following real-time video-conferencing case conferences (Haozous et al. 2012, Kim & Driver 2015). Comparative and interventional studies to assess clinical service feasibility of telehealth showed that for diagnosis reliability, asynchronous images were acceptable for ENT (Smith, Perry, Agnew et al. 2006) and cancer screening (Friedman, Downing, Chino et al. 2010), as was face-to-face compared with real-time video-conferencing for mental health diagnosis (Shore, Savin, Orton et al. 2007). Although a large sample size of 321 participants increased reliability of findings (Friedman et al. 2010), the other studies were limited by non-randomisation (Smith et al. 2006), potential screener bias (Smith et al. 2006), and delayed comparison interval (Shore et al. 2007). Therefore, whilst these results are promising in terms of telehealth feasibility for health services, study limitations impact their conclusiveness.

Discussion

Key findings

This review highlights that telehealth is being used across the world to manage a wide variety of chronic conditions experienced disproportionally by Indigenous peoples, but lacks conclusive evidence as to its overall effectiveness, acceptability and feasibility. The existing literature provides some evidence for the effectiveness of telehealth in terms of health outcomes from a Western biomedical perspective. This was seen by reductions in hospitalisations, decreased unnecessary transfers, and increased health management adherence. However, the acceptability of telehealth appears somewhat mixed for the Indigenous peoples utilising such services, and it is not clear whether or how it can enable health professionals to enact a holistic model of health. Telehealth appears to be feasible for health services in terms of healthcare delivery, and healthcare professionals have mostly positive views of using telehealth. Key gaps reflect a lack of research from a holistic health perspective with a need for more focused research on the cultural competency of healthcare professionals and systems in relation to telehealth, and how cultural safety is experienced.

Health Systems: health economics and telehealth with Indigenous people

Telehealth is not a health system, however it is a key component of many systems delivering healthcare to some of the world's most vulnerable people and therefore needs thoughtful consideration to assess functionality. The (WHO 2010b) presents five key components of a well-functioning health system: improving health status; defending populations against what threatens its health; protecting people against consequences of ill health; providing equitable access to people-centred care; and making it possible for people to participate in decisions about their health and health system. This review highlighted that telehealth can improve health status as seen by improvements in diabetic clinical indicators (Lorig et al. 2010, Turner et al. 2013). Public health measures of health promotion, incorporating telehealth can result in increased involvement with health services (Levine et al. 2009, Elliott et al. 2010, Robinson et al. 2011, Brooks et al. 2012), thereby potentially defending Indigenous peoples against the threat and risks associated with chronic disease. The review also highlighted that telehealth results in increased screening rates (Mansberger et al. 2015) and health service utilisation (Elliott et al. 2010), potentially protecting people against the consequences of ill health. Similarly, in this review, telehealth enabled more equitable access to specialist services not otherwise available in some geographical locations. Lastly, it was evident that Indigenous people were able to participate in decisions regarding the development of telehealth services in their local community, and thus better participate in decisions about the healthcare they receive (Helm, Koyanagi, Else et al. 2010, Doorenbos, Demiris, Towle et al. 2011).

This review did not evaluate the health economics of telehealth. It is important to note that the decision to incorporate telehealth into the suite of modes of delivery of health care based purely on economic benefits as an argument for use (eg. (Whited, Datta, Aiello et al. 2005)), or by non-Indigenous people and systems (eg. (Helm et al. 2010)), fails to consider Indigenous ways of knowing, being and doing and as such cannot be assumed to be generalisable to Indigenous peoples. Further, it is assumed that a reduction in health service cost does not necessarily equate to increasing effective and efficient quality care. If cost is saved to health services, is there a cost to the Indigenous peoples using the service? When people are happy not having to travel, is it costing them their health?

Holistic health: does telehealth address this multidimensional concept?

Indigenous people across the world value a holistic, multi-dimensional concept of health that Helen Milroy (Australian Indigenous Doctors' Association 2010) describes as including physical, psychological, social health and wellbeing, spirituality, and cultural integrity. It is important to note that whilst there are some inherent similar characteristics shared between Indigenous peoples across the world, for example their connection to land and holistic health beliefs, significant differences also exist between cultures, like language and rituals. Indigenous peoples are therefore more likely to experience better health outcomes when healthcare is not compartmentalised, and delivered from a comprehensive model of primary health care to address all aspects of Indigenous health, including social and emotional health and wellbeing. While this review found telehealth is somewhat effective as a modality of healthcare delivery for chronic condition management with Indigenous peoples, the included studies addressed only singular aspects of health and wellbeing and did not encompass a holistic standpoint. For example, physical and psychological health were addressed, albeit singularly, but social health, wellbeing, spirituality and cultural integrity were not addressed. The physical aspects of holistic health could be optimised with telehealth, and whilst psychological health was addressed, it did not translate well with telehealth. It seems the cultural competency of telehealth set up and users, in terms of how holistic health care can be provided, are yet to be determined.

The cultural interface: barriers and facilitators to telehealth

This review identified where the ability of healthcare professionals and systems to negotiate the cultural interface may increase the acceptability of telehealth from a cultural perspective for Indigenous clients. Mason Durie (2004) describes the interface as being where Indigenous knowledge intersects with scientific knowledge, in this instance, a Western biomedical standpoint. It is well known that cultural factors influence the way in which Indigenous peoples access and engage with health services and non-Indigenous healthcare professionals (Jones 2002, Scrimgeour & Scrimgeour 2008). Further still, healthcare is more often than not delivered within cultured space often based on a Western biomedical system of care that does not allow for different concepts of health and healing. Telehealth is no exception.

Culturally competent healthcare professionals (Gibson, O'Donnell, Coulson et al. 2011, Mooi et al. 2012, Venter et al. 2012), and health service delivery (Jernigan & Lorig 2011) may facilitate culturally acceptable telehealth. For the non-Indigenous health professional, '…working at the cultural interface requires critical questioning of professional assumptions based on Western knowledge while simultaneously being open to learning about Indigenous knowledges' (Thomas, Gray & McGinty 2011). When language barriers (Hiratsuka et al. 2013), inability to form trusting relationships (Gibson et al. 2011), cultural factors and discomfort with information and communication technologies (Mooi et al. 2012) are barriers to delivery and receiving effective healthcare, other modalities must be implemented.

Therapeutic relationships: trust and rapport

Relationship development was key for both Indigenous clients and healthcare professionals in many of the studies. This was highlighted by constant reference to its importance: for better health outcomes; cultural appropriateness; and facilitating telehealth uptake. Essentially, the acceptability of telehealth and its ability in having the potential to improve healthcare, is dependent on its ability to facilitate and enhance these vital relationships (Hiratsuka et al. 2013). Two studies focused on different aspects and perspectives of telehealth (Gibson et al. 2011, Venter et al. 2012) suggested initial consults be face-to-face to foster relationship development. Telehealth may be an acceptable modality to health care delivery because it enables Indigenous peoples to receive treatment in their home community. However when actually given a choice over how their health care is delivered, does this suggest that Indigenous peoples would prefer a face-to-face approach? In contrast, when discussing the use of telehealth for cancer management, the healthcare professionals in one study assumed and agreed '…*that it [telehealth] is an appropriate model that is well received by Indigenous patients*' (Mooi et al. 2012). How this assumption was made is unclear. For this study, relationship importance was regarding the benefits of telehealth for healthcare professionals. It was reported telehealth enabled professional relationships and therefore enhanced collaborative care. When clients want face-to-face, time, trust, and ultimately relationships (Hiratsuka et al. 2013), it is difficult to determine which is the most appropriate model of healthcare delivery for Indigenous peoples. Does the potential of telehealth to bridge a physical divide make it a culturally appropriate and acceptable healthcare model? Further still, can telehealth bridge a cultural health divide?

Strengths and Limitations

To our knowledge, this is the first systematic review of studies focused on the use of telehealth for chronic condition management with Indigenous people from around the world. Ambiguity exists regarding a precise definition of both culturally competent care and the holistic management of chronic conditions. The identification of specific aspects of telehealth that are both effective and acceptable for use with Indigenous peoples will assist in guiding health policy and planning. Although every effort was made through our comprehensive systematic search approach to identify all relevant research available, some studies may not have been identified. Furthermore, the studies in this review had methodological limitations. Whilst addressing health economics by assessing the efficacy of telehealth is very important, it was beyond the scope of this study. Recent reviews (Mistry 2012, De La Torre-Díez et al. 2015) suggest inconclusive evidence due to a lack of randomised control trials, small sample sizes and the absence of quality data and appropriate measures.

Future research

The present evidence highlights gaps in current research regarding the use of telehealth as a modality for healthcare for chronic condition management with Indigenous peoples. The review provides guidance on the areas to which future research is mostly likely to be useful. The effectiveness of health care for Indigenous peoples has proved to be most successful when aimed at addressing holistic health needs (Commonwealth of Australia 2013). This may be addressed by a shift in focus whereby health systems and healthcare professionals value and incorporate the knowledge of communities and individuals with lived experience via community consultation and through embedding Indigenous knowledges into health care training. Respectful consultation will highlight the perspective of those who are most affected by telehealth, and in essence will inform more appropriate and acceptable telehealth initiatives (Gibson et al. 2011). A better understanding of telehealth approaches and resultant health outcomes is needed (Hiratsuka et al. 2013), and similar to other reviews (Ekeland, Bowes & Flottorp 2012), we suggest that more rigorous and larger studies of a wider range of Indigenous peoples is needed to produce more conclusive evidence for the effectiveness of telehealth for beneficial health outcomes with Indigenous peoples. It appears that telehealth is promising, but that more work needs to be done to ensure cultural safety and the cultural competence of health professionals and services with research considering the contexts in which telehealth is being used in the hope that it is conceptualised to uphold culturally safe practices.

Conclusion

Telehealth is a multifaceted concept involving all aspects of the health system. Its implementation and use as a modality to healthcare is complex and it is experienced differently on all accounts by services, healthcare professionals and end users. In addition, the use of telehealth with Indigenous peoples raises important considerations of cultural appropriateness and acceptability. This review illustrates issues of cultural differences in healthcare delivery. It highlights differing levels of relationship importance as well as the need for community involvement and culturally competent care when incorporating telehealth in service delivery for Indigenous peoples. Recognition and consideration of cultural competencies will support telehealth in progressing beyond simply bridging a physical divide to having a more positive influence on health outcomes for Indigenous peoples. Indigenous peoples have a right to receive health care from culturally competent healthcare professionals and systems. Further still, Indigenous peoples have the right to experience culturally safe care. This can be facilitated through respectful listening to and meaningful engagement with Indigenous peoples and communities and by the delivery of care by Indigenous people. All stakeholders share in the responsibility for implementing and maintaining effective and acceptable telehealth for Indigenous people requiring chronic condition management.

Chapter summary

This review found that while telehealth is promising, a lack of robust studies make tangible conclusions about culturally competency difficult. A better overall understanding of telehealth use with Indigenous peoples, including delivery of culturally competent health care, true consultation and cultural competency of the professionals involved, would be helpful. Telehealth may have the potential to improve healthcare for Indigenous people, however the modality needs to be culturally competent and the care received must be culturally safe.

CHAPTER 5 – Burns injury models of care: a review of quality and cultural safety for care of Indigenous children

Safety and quality in the systematic management of burns care is important to ensure optimal outcomes. It is not clear if or how burns injury models of care uphold these qualities, or if they provide a space for culturally safe healthcare for Indigenous peoples, especially for children. This chapter presents a critique of the quality and cultural safety of burns injury models of care that guide burns care for Indigenous children. The term Indigenous is used throughout this paper to represent Indigenous people from around the world. The original work presented in this chapter has been published in the peer-reviewed literature.

Citation

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Attribution of Authorship

Authors SF (85%), JG, TM, KH, RI all contributed to the conception and design of this systematic review. Data collection was completed by SF (100%). Analysis and interpretation of research data was performed by SF (85%) and contributed to by authors JG, TM, KH, AH, WT, KC and RI. Drafting of the manuscript was completed by SF (80%), and revision of significant parts of the work so as to contribute to the interpretation was contributed to by SF, JG, TM, KH and RI.

Introduction

Around the world, burns injury is a leading cause of morbidity (Peck 2011), with children particularly at risk (Akita, Nakagawa, Tanaka et al. 2005, Sadeghi-Bazargani, Mohammadi, Amiri et al. 2016). People living in lower to middle income countries (Peck 2011, Alnababtah, Khan & Ashford 2016, Sadeghi-Bazargani et al. 2016) and those who identify as Indigenous (AIHW 2011a, Tovell et al. 2012, BRANZ 2014, Alnababtah, Khan & Ashford 2016, Brussoni, George, Jin et al. 2016) are at greater risk of burns injury. Australian research has shown a greater proportion of Aboriginal than non-Aboriginal children sustain full thickness burns and burns affecting more than 20% of the total body area (Möller et al. 2017), similar to the increased incidence of burns injury for Aboriginal peoples living in non-metropolitan areas of Canada (Brussoni et al. 2016). Health services continue to struggle to provide appropriate care to marginalised peoples (Anderson et al.

2016) and this coupled with the over representation of burns in such populations, can challenge health systems globally to effectively resource and deliver suitable care.

Burns care is a collaborative and multidisciplinary process that, depending on burns severity, may require specialised facilities staffed by experts in burns care (Al-Mousawi et al. 2009). The specialised nature of burns care often results in hospital admission (Peck 2011), frequent and sustained follow-up care and rehabilitation (Esselman 2007). This specialist, multidisciplinary burns care required for good outcomes is guided by various system and service documents. One key set of documents include those relating to the clinical management of burns injury. These documents are usually discipline specific and guide health professionals in their provision and decision making regarding direct clinical care (Foster 2014).

In contrast to these more clinical documents, guidance relating to overall system and service contexts for burns care is provided through burns injury models of care.

Models of care are not discipline specific nor do they have a specific clinical focus. A model of care is more of a multifaceted concept which broadly defines the way health services are enacted and delivered (Queensland Government 2004). Models of care outline evidence-based, best practice patient care delivery through the application of a set of service principles across identified clinical streams and patient flow continuums (Queensland Government 2004). While such principles are commonly recognised, ambiguity continues to exist regarding a strict definition of what constitutes a model of care (Davidson, Halcomb, Hickman et al. 2006). For the purpose of this review, a model of care will be defined as an evidence informed philosophical document that provides an overarching framework for burns injury management for a given jurisdiction.

Though models of care for burns injury exist, what constitutes evidence based best practice burns care from this overall system and service perspective remains unclear. Primary research describes specific aspects of burns care, for example post-acute care and the use of telehealth (Smith, Kairl & Kimble 2002, Smith et al. 2004), education and follow-up (Finlay, Hendrie, Allison et al. 2014) and the medical management of a burns injury (Kim, Martin & Holland 2012). Apart from a national review of burns care in the British Isles there is little literature that critiques and maps *overall* burns care for any given jurisdiction; the British Isles review stresses an urgent need for a coherent national burns care strategy (National Burn Care Review Committee 2001). Overall, it is unclear if existing international, or in particular Australian burns injury models of care purporting to represent best practice, are evidence informed, or have been evaluated to assess their ability to facilitate safe and high-quality care.

Safety and quality are implicit in models of care and are equally important for consumers of care as well as for health systems, services and professionals. High quality healthcare facilitates increased effectiveness and efficiencies (Joynt, Harris, Orav et al. 2011). This is true for the clinical component of burns management in regards to increased efficiencies in Australian jurisdictions (Wong, Heath, Maitz et al. 2004, Finlay et al. 2014, Finlay, Phillips, Allison et al. 2015). Internationally, governmental commissions inform safety and quality in healthcare (ACSQHC , Health Quality & Safety Commission New Zealand , The UK National Patient Safety Agency , United States of America). In Australia, the Australian Safety and Quality Framework Health Care informs a vision for safety and quality in healthcare (ACSQHC 2010a). Frameworks such as these provide guidance and aim to achieve safety and appropriateness of healthcare in partnership with consumers (ACSQHC 2017a). Specific quality improvement documents exist for burns care (American Burn Association 2017). How the concepts of safety and quality have been achieved, relate to or provide specific guidance to the systems and service management of Indigenous peoples with a burns injury remains unclear.

Differences in knowledge systems exist (Durie 2005). Science, a dominant global knowledge system, is in stark contrast to Indigenous knowledge systems of knowing, being and doing (Martin 2003). An important consideration where healthcare is directed at Indigenous peoples, is how clinical safety may also relate to cultural competency and cultural safety. Cultural competency is the skill and capacity of healthcare professionals and systems to respond to cultural differences (Bainbridge et al. 2015). Cultural safety is an experiential, contextual theory developed by Maori in the New Zealand healthcare context to address the ways in which colonial practices, organisations and policy shape and negatively affect the health of Maori peoples (Ramsden 2002). The theory has since been adopted in other countries including Canada (National Aboriginal Health Organization 2008) and Australia (Bainbridge et al. 2015), with evidence of improved healthcare outcomes (Bainbridge et al. 2015).Similarly, outcomes following a burns injury are associated with many factors (Kent, King & Cochrane 2000, Sheridan et al. 2000, Anzarut, Chen, Shankowsky et al. 2005, Sheridan et al. 2012, Van Der Wal, Vloemans, Tuinebreijer et al. 2012) and extends beyond simple issues of timely access to high-quality and specialist care. Within the context of burns care and for Indigenous peoples, cultural safety or lack thereof, also contributes to health outcome. As such, it is anticipated that if a burns injury model of care is of a high-quality and provides opportunities for health services and professionals to enact care that is culturally competent, there is potential for better health outcomes for those receiving care. Effective examples of culturally competent models of burns care are poorly described in the literature.

This review aims to describe the existing Australian and international burns injury models of care that guide burns care management, particularly that of Indigenous children, and to critique and assess these models of care for their ability to facilitate safe, high-quality burns care.

Methods

Search strategy

The search strategy included evidence syntheses and grey literature. The research focus and relevant search terms were developed iteratively in consultation with a supervisory group and refined during the literature search process. An initial search was conducted of the electronic databases: CINAHL, Scopus, Informit, and Web of Science. Keywords included: burn* AND "model of care" OR "practice guideline" OR "practice framework" OR "care standard". Additional key papers, guidelines, care standards, models of care and policy documents were sourced from health organisations and relevant associations as well as a search through reference lists and in Google Scholar. Literature was included if it reported on the system and service perspective of burns injury, with any focus on paediatrics or the care of Indigenous peoples. Because this review focuses on burns care from a systems and service perspective, literature limited to descriptions of the clinical management of burns injury were excluded, as were literature limited exclusively to adult patient care. This review reports in narrative form, a critique of documents from a wide variety of sources.

Analysis framework

In addition to the variable definitions of what constitutes a model of care, there also exists no specific tool for use to critique and appraise models of care. It is also important to acknowledge that Indigenous health knowledge cannot be verified by Western biomedical knowledge, nor can science be adequately assessed according to the tenets of Indigenous knowledge. Each is built on distinctive philosophies, methodologies and criteria (Durie 2005). The writing team consisted of Indigenous and non-Indigenous researchers: extensive discussion occurred to determine an analysis framework that interfaced the two knowledge systems. Interface research endeavours to eliminate the power imbalances and ensure equal embedding of knowledge systems. In the absence of a suitable overarching analysis framework to critique models of care and compounded by the complexities of different knowledge systems, two tools were chosen following an appraisal of different tools: one reflecting Indigenous theory and the other for analysis of scientific aspects.

Indigenous health knowledge was considered through the cultural safety principles (Table 3) in healthcare as described by Taylor and Guerin (Taylor & Guerin 2014). The principles enable a critique of the documents in terms of how they consider Indigenous ways of knowing, being and doing(Martin 2003). Deductive analysis was used to assess how burns injury models of care provide, or not, opportunities for healthcare professionals to enact culturally competent care.

Western biomedical knowledge was critiqued through the National Health Medical Research Council (NHMRC) standards for clinical practice guidelines (NHMRC 2011). Given models of care require quality and safety in healthcare to be met, these guidelines (
Table 4) are appropriate and can be transferred and applied to enable a critique of the models of care.

Table 3 - Cultural safety principles

Principle	Definition	In-Practice
Reflexivity	reflect on practice, mutual respect	established processes for health professionals to actively reflect on practice
Dialogue	true engagement and consultation	building rapport and dialogue with family alongside consideration of kinship arrangements and decision making structures, particularly as they relate to children
Power	minimising power differentials and maintaining human dignity	including Indigenous health workers in multidisciplinary teams mechanisms to address issues of implicit bias amongst multidisciplinary team members
Decolonisation	acknowledging the key role of a colonising history in contemporary health outcomes for Aboriginal and Torres Strait Islander peoples	ensuring equity in health care to achieve equity in health outcomes
Regardful care	provide care that is regardful of culture and challenges the status quo of providing care that is regardless of culture	patient-centred care; where the context for the child and their family drives care decisions

Table 4 - NHMRC standards for clinical practice guidelines

	Standards
Clinical justification	provide guidance on a clearly defined clinical problem based on an identified need
Multidisciplinary	be developed by a multidisciplinary group that includes relevant experts, end users and consumers affected by the clinical practice guideline
Conflicts	include a transparent process for declaration and management of potential conflicts of interest by each member of the guideline development group
Scientific evidence	be based on the systematic identification and synthesis of the best available scientific evidence
Recommendations	make clear and actionable recommendations in plain English for health professionals practising in an Australian healthcare setting
Navigation	be easy to navigate for end users
Consultation	undergo a process of public consultation and independent external clinical expert review; and
Dissemination	incorporate a plan for dissemination including issues for consideration in implementation

Results

The search (Figure 2) resulted in six documents being identified (Table 5). Whilst not all documents were titled a 'model of care', they each meet the inclusion criteria. That is, they provided an overarching philosophical framework for burns care from a systems perspective for a specific jurisdiction. They also had the potential to guide the provision of care for Indigenous peoples and children.

Figure 2 - Search results

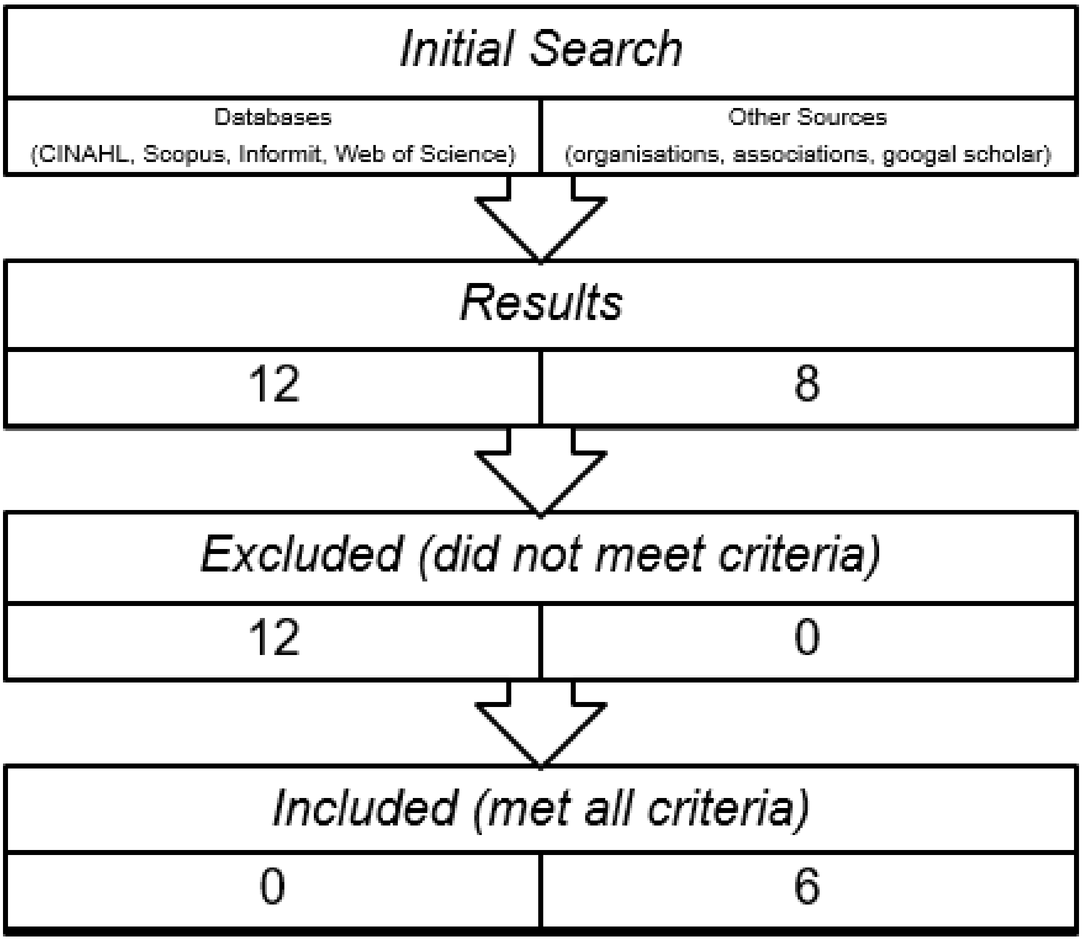


Table 5 - Identified documents reviewed

Origin	Contributor/Author	Title	Date	Focus
Europe	European Burns Association	European Practice Guidelines for Burn Care	Version 3 2015	Guidelines applicable for adults and/or children with a burns injury.
UK	National Network for Burn Care	National Burn Care Standards	Revised January 2013	Standards cover the whole of the burns care pathway and take account of the specific needs of children and adults.
Aust	Department of Health, State of Western Australia, Injury and Trauma Health Network	Burn Injury Model of Care	2009	Proposed models of care for Burns Injury for all WA burns injured patients. Adult and paediatric.
Aust	NSW Agency for Clinical Innovation	NSW Statewide Burn Injury Service Model of Care	2011	The model of care has been designed to address the provision of burns care for adult and paediatric patients. Where specific requirements for burns care for paediatric patients were identified, these have been indicated in the relevant areas of the model.
Aust	SA Health, Women's and Children's Hospital	Paediatric Burns Service Guidelines	Updated 2014	The Paediatric Burns Service is responsible for inpatient and outpatient treatment of children up to 16 years of age.
Canada	The Montreal Children’s Hospital	The management of pediatric and adolescent burns trauma	Revised 2014	Guidelines for the management of child burns trauma.

Cultural safety analysis

Overview

Cultural safety was addressed in this review first to ensure the review was not privileging Western biomedical knowledge. Deductive analysis was used to assess how each of the principles introduced in Table 3 were addressed in the identified models of care (Appendix 8). The analysis identified marked differences between documents with respect to recording the principles of cultural safety, with documentation of both direct and indirect guidance for healthcare professionals providing care that may/may not be experienced as culturally safe.

Principles

Only two of the documents (NHS National Network for Burn Care 2013, European Burns Association 2015) addressed all five cultural safety principles and not one principle was addressed by all six documents. **Reflexivity** examples were found in four models of care (Government of Western Australia 2009, ACI 2011, NHS National Network for Burn Care 2013, European Burns

Association 2015) and highlighted the need for health professionals to reflect on their practice, however were not specifically focused on Indigenous or other cultural needs. Quality improvement activities were at the core of reflexivity. Almost all of the documents addressed the cultural safety principle of dialogue (European Burns Association 2015, NHS National Network for Burn Care 2013, Government of Western Australia 2009, ACI 2011, The Montreal Children’s Hospital 2014).

Dialogue is a principle in this review that refers to health service and professional ability to partake in and enable engagement and consultation with patients and families. Concepts of dialogue in the documents related to all aspects of the burns patient care journey: prevention (Government of Western Australia 2009), admission (The Montreal Children's Hospital 2014), inpatient (European Burns Association 2015, NHS National Network for Burn Care 2013, ACI 2011), discharge (ACI 2011, The Montreal Children's Hospital 2014, European Burns Association 2015) and rehabilitation (ACI 2011, European Burns Association 2015).

The concept of **power** as a cultural safety principle in minimising power differentials and maintaining human dignity was identified in almost all of the models (European Burns Association 2015, NHS National Network for Burn Care 2013, ACI 2011, Government of South Australia 2014, The Montreal Children’s Hospital 2014). At the core of this principle, was the empowerment of patients and their family. The power relations that models of care set-up between clinicians and families however, make achieving true power equilibrium challenging. Furthermore, the influence of power on healthcare interactions may make empowering those receiving care also challenging.

Almost all of the documents (European Burns Association 2015, NHS National Network for Burn Care 2013, Government of Western Australia 2009 and Government of South Australia 2014), indirectly considered **decolonisation** by acknowledging the key role of a colonising history in contemporary health outcomes for Indigenous peoples. The models mostly described consideration of factors beyond having a purely medical focus and providing equitable care as addressing the cultural safety decolonisation principle. All documents addressed the provision of **regardful care** including the provision of holistic care (NHS National Network for Burn Care 2013, European Burns Association 2015) and culturally sensitive care (ACI 2011).

NHMRC standards for clinical practice guidelines analysis

Overview

Deductive analysis was used to assess how the documents met the NHMRC standards for clinical practice guidelines (Appendix 9). The analysis found the guidelines were met differently across the documents, with no one document meeting all eight. All documents contained clear and actionable recommendations for health services and healthcare professionals, however the processes used for development of the documents were mostly unrecorded.

Standards

All documents highlighted some **clinical justification** for a burns injury model of care and all provided guidance for burns injury management from injury through to rehabilitation by specialists in multidisciplinary teams. Two of the five documents (Government of Western Australia 2009, ACI 2011) specifically identified need for a burns injury model of care, and other needs included incidence of burns injury and at risk populations. All documents were developed by teams of **multidisciplinary** healthcare professionals, with one document listing a consumer (ACI 2011). It was not clear how the teams contributed or how the contributors were designated to this role. The NHMRC (NHMRC 2011) calls for a declaration of **conflicts**; however, there were no declaration of potential writer conflicts in the development groups, nor documentation of management of potential conflicts by contributors in any of the reviewed documents. Furthermore, it was not clear if there was equal participation between contributors as only one of the documents (ACI 2011) recorded a systematic process of development (ACI 2011).

The NHMRC (NHMRC 2011) also require models be based on the best available **scientific evidence**, however there was inconsistency between documents with respect to the references used and not all aspects of care were referenced. One document (European Burns Association 2015) highlighted a lack of rigorous evidence for some aspects of burns care and suggested clinical consensus was used to inform practice. Conversely another document (ACI 2011) reported the application of evidence-based practice was essential to achieve positive patient outcomes.

The documents all made specific **recommendations** in plain English relevant to their jurisdiction for healthcare professionals. The Canadian (The Montreal Children's Hospital 2014) document was available in French (a legal requirement in Canada), however no other model was offered in a different language. The end users of these documents are the health service and healthcare professionals. For ease of **navigation**, all documents were separated into different sections either by profession or burns management stage, however overall presentation and inclusion of detail varied. Different methods of **consultation** and review were implemented in the documents. Three documents (ACI 2011, NHS National Network for Burn Care 2013, European Burns Association 2015) that sought review by wider membership did not report a process for responding to feedback. Two documents (Government of Western Australia 2009, Government of South Australia 2014) did not specify a consultation process, although one of these was a proposed model of care and may engage a consultation process further on. The incorporation of a plan for dissemination including issues for consideration in implementation was not recorded in any of the documents, aside from one (Government of Western Australia 2009). This document was a proposed model and recorded an extensive implementation list. In a report by the Government of Western Australia (Government of Western Australia 2015), the burns injury model of care has reached a level of substantial implementation; meaning that most of the recommendations of the model of care have been implemented.

Discussion

This review provides a unique critique of burns injury models of care with a focus on Indigenous children, from a quality and safety perspective using both Indigenous health knowledge and Western biomedical knowledge. The review is limited by the possibility that other burns injury models of care may exist but were inaccessible for the purpose of this review. Furthermore, it is acknowledged that health services and healthcare professionals are influenced by other documents that may not fit within the confines of a model of care per se, but rather sit alongside. This is especially true for profession specific guidance and related regulatory requirements. Lastly, no child specific cultural safety analysis framework was identified for use in the analysis.

Burns care can be complex and require a multidisciplinary approach over extended periods. The care of a child in the context of a family and taking into consideration growth and development heightens the complexities of burns care. The care of Indigenous peoples requires the inclusion of holistic approaches to care that sit outside of Western biomedical models. There is clear opportunity in burns care for improvement, with increased focus on patient needs (Government of Western Australia 2009).

Burns injury models of care are multifaceted documents that guide the way burns care is delivered in a specific jurisdiction (European Burns Association 2015, NHS National Network for Burn Care 2013, Government of Western Australia 2009, ACI 2011, Government of South Australia 2014, The Montreal Children’s Hospital 2014). It is implicit these models of care address quality and safety across all aspects, including in their development in order to facilitate such care. Culturally competent models of care consider concepts of health that extend beyond the Western biomedical health system. This guidance allows for the provision of equitable care; in contrast to care being based entirely on equality. This review demonstrated that publicly available burns injury models of care do not address all aspects of quality and safety.

Quality in models of care

The NHMRC standard for clinical practice guidelines (European Burns Association 2015) provides a framework to analyse burns injury models of care from a quality perspective; however this framework lacked consideration of culture. Overall, quality was difficult to determine due to key indicators of quality being in part, or completely absent, in the documents addressed by the review. There were no clear descriptions of how the synthesis of best available evidence informed the documents, making comparisons difficult. Best practice recommendations do exist (Kavanagh

2013, Chu 2015, Campbell 2015a, 2015b, 2015c, 2015d, Shama 2016), however where and how these recommendations have translated into the reviewed burns injury models of care was unclear.

The American Burn Association facilitates a verification process for burns centres detailing overall burns care systems including outcomes, infrastructure and process (American College of Surgeons 2014) to enhance quality. Although not US based, none of the models of care reviewed made reference to this standard, or similar accreditation type processes. Furthermore, whilst the models seemed mostly to be created by teams of specialist clinicians, for most, they did not document a process of consultation with external parties. Consultation with external parties, including consumers, is important for quality and transparency and provides the opportunity for fair contribution and different knowledge perspectives to be considered. This raises the question: if models of care are mostly clinician informed, how do they incorporate evidence and do they meet the prescribed standards of quality for each given jurisdiction and/or population group?

Safety in Models of Care

Health outcomes for Indigenous people are more likely to be enhanced when healthcare is experienced as culturally safe (Downing, Kowal & Paradies 2011, Bainbridge et al. 2015). This review demonstrated burns injury models of care address only some of the principles of cultural safety. It is anticipated that if a burns injury model of care provides opportunities for health services and healthcare professionals to enact care that is culturally competent, there would seem potential for better outcomes following a burns injury. Experiences of culturally safe burns care may help ensure improved and ultimately more economical long term outcomes for Indigenous children, including the potential for reduced loss to follow-up, increased access to rehabilitation, more efficient services and increased effectiveness. Consideration of kinship arrangements is necessary to achieve these outcomes. For example, considering beyond a Western nuclear family model to a more collective community focus. In the Australian context, the Cultural Respect Framework (Australian Health Ministers' Advisory Council 2012) highlights relevant quality healthcare items relating to Aboriginal and Torres Strait Islander people which includes amongst many items, mechanisms to support the delivery of culturally safe healthcare. It is unclear how the Australian burns injury models of care address items in this framework. Similarly, the ability of international health systems and services in providing mechanisms for culturally safe burns injury management is vague.

There appeared to be limited or no cultural consultation in the models of care reviewed and in terms of their development, it is uncertain if any Indigenous people contributed or if they did, in what capacity. One model (Government of Western Australia 2009) reported needing to consult with Aboriginal peoples regarding the development of burns injury prevention materials and included an incomplete Aboriginal impact statement. Similarly, where the models provided an opportunity for healthcare professionals to provide care with regard to culture, directions were mostly implicit and not mandatory.

Another emphasis of cultural safety is on the healthcare interaction. While burns injury models of care provide guidance to health services and healthcare professionals from which to enact burns care, the delivery of care and subsequently the healthcare interaction is dependent on the individual. It is the individual health professional's level of empathy and capacity for reflective practice in providing healthcare that is or is not experienced as culturally safe (Ramsden 2002). These qualities contribute to health professionals' understanding of the process of culture, identity and wellbeing and includes reflexivity, whereby the health professional acknowledges how power imbalances or relationships contribute to culturally unsafe practices (Richardson & Carryer 2005). Therefore, although cultural safety is conceptualised in the healthcare interaction, it is vital that cultural safety principles be manifest in health system and service documents, which in this instance are the burns injury models of care. It is the combination of the ability of burns injury models of care to facilitate safe, high-quality care and the individual health professionals' implementation of that guidance that is a true measure of cultural safety. In addition to the lack of cultural safety in the burns injury models of care reviewed, how these prescriptions of care are enacted by healthcare professionals for each jurisdiction has not been explored. As a result, it remains unclear if Indigenous children are receiving safe, high quality burns care from a system, service or individual level.

It is well documented that Indigenous peoples and those living in rural and remote areas experience burns injury at a higher rate than people living in metropolitan areas (AIHW 2011a, Möller et al. 2017). This review also recognised that burns injury models of care provide guidance for the burns care of Indigenous children residing in rural and remote geographical locations without adequate consideration of the availability of healthcare and other services in these communities. Patient assisted transport schemes were addressed in the models and do provide support to those families who experience difficulties related to geographical isolation. These schemes do not address an Indigenous person's connection to Country and family, and it is unclear in the models whether or how services might be accessed closer to home in order to minimise the need for travel. Providing services in regional and remote areas can be expensive, however there is likely to be a significant impact on health and wellbeing when multiple family members are away from home for extended periods of time.

What should a burns injury model of care include?

This review highlighted gaps related to safety and quality in the current burns injury models of care that inform healthcare provided to Indigenous children. The development of a model of care needs consultation with key stakeholders and consumers of care. Furthermore, incorporation of all health knowledge resources and the combination of clinical and cultural aspects is imperative as being culturally secure is critical for Indigenous children's wellbeing. Milroy's (Australian Indigenous Doctors' Association 2010) dimensions of holistic health: physical, psychological, social, spiritual and cultural could provide the basis for a model of care and has culture as the centre of health as per current National Aboriginal and Torres Strait Islander Health Plan (Trewin 2006). A focus on 'patient-centred care that is respectful of, and responsive to the preferences, needs and values of consumers' will help facilitate high quality and culturally safe models of burns care (ACSQHC 2010b).

How do we develop a safe, high quality model of care for Indigenous children?

The development of a model of care needs consultation with key stakeholders and consumers of care. Cultural safety needs to be reflected and clearly articulated in the documents that guide burns care. To enable such a purposeful approach to cultural safety, expectations of cultural safety need to be embedded in policy, health systems and at service levels. To facilitate the development of such guidance, an accurate account of what guides the burns care delivered in tertiary paediatric burns units across Australia is needed; along with how this guidance is implemented. Durie's principles of research at the interface of knowledge systems (Durie 2005) are well aligned to the development of a safe, high quality burns injury model of care. These principles include: mutual respect, with recognition of the validity of each system of knowledge; shared benefits, where Indigenous communities share in the benefits; human dignity with cultural and spiritual beliefs and practices reinforced; and discovery where innovation and exploration using Indigenous methodologies and scientific methods work together.

With a safe, high quality burns injury model of care, implemented by culturally competent healthcare professionals, there is the opportunity for equitable health outcomes. There is the chance that a child's readmission to hospital for infection will not occur and a surgeon's skin graft will more likely be successful. Along with these better health outcomes, the effectiveness and efficiency of burns care may be enhanced, and benefits to the health system may be achieved.

Conclusion

This review has highlighted gaps concerning safety and quality in documented care pathways for Indigenous peoples who sustain a burns injury and require burns care, and highlights the need for the investigation of current practices in burns units who treat Aboriginal and Torres Strait Islander children. Some, but not all, aspects of cultural competence were addressed in the models. The question still remains, is cultural safety facilitated or mitigated by the application of the guidance? An investigation of current health systems, services and practices in the burns units across

Australia will provide the basis for the development of a national burns injury model of care that is informed on the premise of mutual respect, shared benefits, human dignity and discovery.

Chapter summary

This systematic review found gaps in terms of quality exist in the current burns injury models of care for Indigenous peoples. Furthermore, burns injury models of care do not explicitly address the means to support an experience of culturally safe care. Further work is needed to explore and develop guidelines that appropriately manage cultural safety in burns care for Aboriginal and Torres Strait Islander children and families.

SECTION B: SUMMARY

In this section I have highlighted factors associated with burns injury and burns care for Aboriginal and Torres Strait Islander children. I then presented published literature reviews on telehealth as an alternative to traditional face-to-face care and an investigation into the models that inform burns care. These reviews identified that burns care via telehealth and existing burns injury models of care do not meet all of the principles inherent in high quality and culturally safe care. In addition, while telehealth may provide some increased efficiencies, it is unclear if this method of healthcare delivery for the care of Indigenous peoples, and in particular that of Aboriginal and Torres Strait Islander children is appropriate.

A disconnect of knowledges manifesting in burns care

The disconnect between world views (Western and Indigenous) manifests in Australia’s healthcare system and services. This is as a direct result of Australia’s healthcare system being predominantly based on Western biomedical knowledges. That is, biomedical approaches, with scientific evidence as the main source of knowledge, informing and guiding healthcare practices in Australia.

This disconnect is evident in healthcare and exists as a divide between explanatory models of health and healing. Burns injury models of care and best practice guidelines are developed within the Western biomedical paradigm. The Western biomedical paradigm, frequently used to guide healthcare practice, is likely to be incongruent with Indigenous health ways of knowing, being and doing (McLennan & Khavarpour 2004). The problem with the conflict and incongruences, is that it leads to issues of poor health and healing for those accessing healthcare. For Aboriginal and Torres Strait Islander children and their families accessing and receiving healthcare for a burns injury, this is a reality. For burns care, this disconnect is expressed in burns injury models of care.

This research project cannot address the social issues that relate to the conflict between knowledges. Nor can it stop the inequity whereby Aboriginal and Torres Strait Islander children experience burns injury at higher rates than non-Indigenous children for which blame could be placed solely on the social determinants of health. However, what informs the burns care children receive and the delivery of care is amenable to change. As such, this research will explore how burns care is delivered and what informs the care clinicians provide, especially as it relates to care for Aboriginal and Torres Strait Islander children and families.

SECTION C: METHODS, FINDINGS AND DISCUSSION

In this section, I begin by describing the overall gaps informing this research and a summary of the main aims and objectives of this research. Two distinct methods were engaged to investigate burns care for Aboriginal and Torres Strait Islander children. At the start of this section I present the overall research design. This is followed by a detailed account of the first distinct method used for investigating burns care with members of multidisciplinary burns teams. This is followed by three results chapters: chapters seven, eight and nine. These include the findings from the analysis of 76 semi-structured interviews conducted with paediatric burns team members. Chapter seven presents an overview of the major themes and sub-themes, and chapters eight and nine include the results of further synthesis of those themes and sub-themes. Chapters eight and nine have been submitted for publication in the *Burns* and *International Journal for Equity in Health* journals respectively. Following these chapters, I present the second distinct method concerning patient journey mapping of which is in manuscript form and has been submitted for consideration for publication in *BMJ Quality and Safety*.

In Section A, the disconnect between Western and Indigenous knowledges was made apparent. In Section B analysis and critique of current evidence informing burns care showed how the conflict of knowledges is manifest in Australia's healthcare system and is evident in the documents that inform burns care. Section A highlighted that in order to explore healthcare for Aboriginal and Torres Strait Islander children, the two knowledges need to be interfaced. This was possible through using a research approach that was not extractive and was accountable to the Indigenous community standards on research so as to honour Indigenous world views, *and* scientific knowledge. The research was guided by a relational accountability that promoted respectful representation, reciprocity, and the rights of the researched. The use of a decolonising agenda strengthened the positioning of this research at the interface of knowledges and provided a space for the disconnect of different ways of knowing, being and doing to be examined.

The final chapter of this section, chapter 11, brings together all aspects, and presents a synthesis and discussion of the main findings. It includes recommendations and ideas for translation into practice as a direct result of this research. It is essential to recall that this research is situated within a larger National Health and Medical Research Council (NHMRC) funded study set in tertiary paediatric burns services around Australia. As such, the methods engaged for this research were carefully articulated to contribute to the overall aims of the study and to complement methods already engaged and planned. Furthermore, the findings from this research will be triangulated with the data from overall project (Appendix 1) and with data from other PhD students.

CHAPTER 6 –Methods to explore the delivery of burns care for Aboriginal and Torres Strait Islander children in Australia

In Section B, I identified gaps in the research evidence regarding burns care for Aboriginal and Torres Strait Islander children (chapters three and four) and identified issues of quality and cultural safety in those documents that inform burns care (chapter five). In this chapter I present the overall aims and two specific objectives of my research. I then discuss how I address the NHMRC Indigenous Research Excellence Criteria (NHMRC 2019) relevant to both research objectives. I describe how my research involved community engagement, identified benefits for Aboriginal and Torres Strait Islander peoples, and specifically considered sustainability, transferability and dissemination. Building on my introduction to interface methodologies in chapter two, in this chapter I extrapolate the practical steps taken to enact this approach.

Interface research methodology provided a space to consider Aboriginal and Torres Strait Islander peoples' ways of knowing, being and doing in consideration of the past and current context of both Australia's healthcare system *and* the scientific knowledge for burns care. I describe in detail, the various ethical considerations that were made for research that is with and for Aboriginal and Torres Strait Islander peoples. Given I am a non-Indigenous health researcher, I demonstrate my application of active reflexivity throughout this research.

I then provide a summary of the specific methods engaged to conduct the first component of the research. In this section I focus on the methods used to ensure consideration of the way evidence in burns care has been, and is currently used and created, and how the processes of burns care impacts on care for Aboriginal and Torres Strait Islander children and families. I also describe how the research processes enabled knowledge creation to improve health outcomes for Aboriginal and Torres Strait Islander children experiencing burns care.

Identifying opportunities for change in burns care

Overall aim

This research aimed to investigate paediatric burns care across Australia, with a specific focus on care for Aboriginal and Torres Strait Islander children, and on factors that inform care.

Specific objectives of this research

The two objectives of this research were to:

1. Investigate how burns care in Australia is delivered in and from tertiary burns units and what informs the burns care that multidisciplinary burns teams provide.
2. Develop and pilot a quality improvement tool to elicit where patient healthcare journeys intersect with professional healthcare at critical points along the burns care continuum, and evaluate if and how this is congruent with Aboriginal and Torres Strait Islander ways of knowing, being and doing in a predominantly Western biomedical paradigm.

By addressing the aforementioned gaps, a reform of burns care for Aboriginal and Torres Strait Islander children and families can be formulated which incorporates Aboriginal and Torres Strait Islander people's holistic values and views of health and healing, and transitions care from a predominantly Western biomedical model of health. The reform will place emphasis on empowering the healthcare recipient (in this case the Aboriginal and Torres Strait Islander child and their family accessing burns care); facilitate a team approach where health professionals each hold an equal stake in the client's health and wellbeing; and ensure healthcare can be experienced as culturally safe. While aspects of all three opportunities are already in place, a culturally responsive coordinated burns care approach is still unclear (chapter three). In Australia, this reflects issues in systemic health systems: including inadequate funding; communication difficulties, and an absence of culturally appropriate health services. Implementing reform in the delivery of burns care is one strategy to narrow the gap between the health outcome inequities experienced by Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians.

This research will provide opportunities to directly inform changes focused on improvement in burns care in Australia. This will be done by:

- informing a culturally competent burns injury model of care;
- identification of high quality and culturally safe health and healing opportunities for Aboriginal and Torres Strait Islander children following burns injury;
- developing recommendations for the provision of culturally safe care leading to improved quality of burns care for Aboriginal and Torres Strait Islander children and families; and
- informing the six actions that are specific to Aboriginal and Torres Strait Islander people in the NSQHS standards.

Community engagement in the research process

Multiple strategies were implemented to ensure the research was conducted using culturally acceptable approaches. The overarching study has an Aboriginal and Torres Strait Islander advisory group to enable community input into the study, and to provide high level oversight of methods and relevance. The group includes health care providers from primary care, including from Aboriginal Community Controlled Health Organisations (ACCHOs), as well as tertiary care providers and Aboriginal liaison units from the participating hospitals. Community members were also invited to participate and the overarching study has gained the support of the peak bodies of the ACCHOs in each jurisdiction.

The importance of Indigenous knowledges and ways of working were central to this research project. In line with this, an informal advisory group advised on conceptualisation, development and approval, data collection and management, analysis, report writing and dissemination of results. In addition to this advisory group, PhD supervisor Dr Tamara Mackean, a Waljen (Aboriginal) woman and public health medical practitioner, provided close direction and oversight of all aspects of the project. The project included, recognised and honoured the knowledge of these significant contributors.

Benefit of this research to Aboriginal and Torres Strait Islander peoples

Inequalities in health and wellbeing of Aboriginal and Torres Strait Islander children are well documented. The accessibility to high quality care for Aboriginal and Torres Strait Islander children hospitalised for burns injuries (twice as often as for other children (AIHW 2012), is particularly important given the complexity of long-term burns care, where access to best quality care is essential in producing good outcomes. It is well documented that many Aboriginal and Torres Strait Islander children experience poor access to mainstream health care systems. As such, this research and potential outcomes are a priority for Aboriginal and Torres Strait Islander peoples.

The potential benefits of this project are far-reaching. They include benefiting each Aboriginal or Torres Strait Islander child and family that access healthcare for burns management in Australia through the consideration of appropriate models of care and systems issues that support or impede the application of such models. By informing the development of a culturally appropriate model of care for burns care and a strategy for use in health services across Australia, it is envisaged that health outcomes will improve. In addition, the healthcare of other injuries or diseases in Aboriginal and Torres Strait Islander children may also be better informed.

Sustainability, transferability and dissemination of this research

The collaboration across health disciplines, depth of expertise and track records of personnel involved in this research demonstrate strong potential for the study’s aims and outcomes to be achieved and affect change. The processes documented, input from multiple levels of the healthcare system and involvement of key stakeholders in burns care across Australia will ensure Aboriginal and Torres Strait Islander children and their families experience health gains. This will result from health systems and healthcare providers enacting models of care for burns management that are culturally appropriate. Aboriginal and Torres Strait Islander communities at large will benefit from transferability to other healthcare settings such as evidence-based practice and more effective health service delivery. Sustainability is achieved by the overarching project with key stakeholder roundtables with clinicians, policy-makers and community to develop a ‘blueprint’ for reform of burns care services.

A unique and strong research collaboration between the researcher and a supervisory panel of experts in epidemiology, Aboriginal health, and medicine and nursing has strengthened this research in an important but under-researched area. Understanding how the healthcare system and professionals deliver care for Aboriginal and Torres Strait Islander children who access burns care will improve the evidence base in this field. The pilot of the patient journey mapping tool provided invaluable insight and perspective into the assessment of quality and cultural safety in burns care, and the exploration of attitudes to care by healthcare providers will enable a complete and contextualised review of burns care in Australia. This study, with a combination of mapping through observation, contextually rich qualitative data, and detailed interview offers a unique opportunity to generate, using a best practice, collaborative approach, important evidence to inform the development of improved models of care for what is an over-represented and vulnerable population. Exploring the complexities of burns care for Aboriginal and Torres Strait Islander children will serve as a model for engaging health system reform that better meets the needs of not only people experiencing disadvantage in Australia, including people of low income, of non-English speaking backgrounds and those living in regional and remote locations, but also the broader population. Further, this research has the potential to have important implications for burns care internationally by informing better models of care. It will be relevant to other first nations’ peoples globally, and is not only relevant to burns care, but for tertiary healthcare in general because it is about having culturally responsive services.

Opportunities to disseminate the findings from this PhD have been sought to maximise transferability into other areas of healthcare for Aboriginal and Torres Strait Islander peoples. This includes results submitted for publication in broad health equity and health quality peer reviewed journals (see publication list on page 7), enhancing transferability into health service delivery. Presentation of the results at relevant national and international conferences (see presentation list on page 9) has also supported transferability into other areas of healthcare, for example at the 13th Australasian Injury Prevention and Safety Promotion Conference. Presentation of results at the Lowitja Institute International Indigenous Health and Wellbeing Conference in June 2019, further enhances opportunities for dissemination and transfer across disciplines. Following the submission of this thesis, submissions to the *Social Science and Medicine* journal which provides an international and interdisciplinary forum for the dissemination of social science research on health are also planned. Further testing of the patient journey mapping tool will assess its use and applicability in tertiary healthcare services for burns care, but also for other conditions requiring care over a continuum therefore increasing is transferability into other settings.

Reflexivity as a method for decolonisation

Decolonising theory presents a method for decolonisation in research practice and also relates to a personal journey for Indigenous and non-Indigenous people. Muller (2014, p. 55) writes about six stages of decolonisation for Indigenous people to heal and find harmony following the havoc of colonisation. These are: rediscovery and recovery; mourning; healing and forgiveness; dreaming; commitment; and action. Muller (2014) also states decolonisation is equally important for those of the settler society, such as me, and as human rights is core to the ethics of this research project, a necessary pathway to follow (Muller 2014, p. 64). For non-Indigenous researchers such as myself, the effects of colonisation in terms of the undermining of Indigenous knowledge are ingrained and unconscious. Considerable effort is required to become aware and then question assumptions that contradict or are challenged by contact with Indigenous peoples (Thomas, Gray & McGinty 2011). Decolonisation provided a framework to deconstruct these processes and outcomes of colonisation (Muller 2014, p. 54). Decolonisation for me was part of my engagement in reflexivity in research and an internal journey beginning some time ago and continuing today. It is how the assumptions about colonisation and Indigenous peoples that permeate my view of the world have been explored. The following is an overview of how I engaged with Muller's (2014, p. 64) stages of decolonisation (and/or the ramifications following):

1. Rediscovery. While I did not rediscover, I discovered and learnt about Aboriginal and Torres Strait Islander people's culture; their ways of knowing, being and doing. This was through engagement in my work, fellow PhD students, my supervisory panel, and my cultural mentors.
2. Mourning. I felt anger, shame and guilt when confronted with the truths and impacts of colonisation. More so in the beginning of my journey; however I still experience such feelings when confronted by such extraordinarily unfair disparities.
3. Healing. This was my working towards feeling more comfortable about my understanding of Aboriginal and Torres Strait Islander people's culture and the process of colonisation. This was through continued conversations and engagement in reflexivity.
4. Dreaming. For me, it was and still is taking the time for my discovering and learning about a culture different to my own and allowing it to happen at its own pace.
5. Commitment. This was my commitment to a better health system, more appropriate services and improved care for Aboriginal and Torres Strait Islander children and their families by contributing to equity in healthcare.

6. Action. I started the process of decolonisation. It was a journey that cannot be accelerated, nor is there an end.

Ethics and site approvals for research

Ethics approval was sought and received from the following committees:

Table 6 - Ethics approvals

Jurisdiction	Committee
Western Australia	· Princess Margaret Children's Hospital 2016139EP · WA Aboriginal Health and Research Ethics Committee WAAHEC HREC 750
New South Wales	· Aboriginal Health and Medical Research Council Ethics Committee 1032/14 · Sydney Children's Hospitals Network Human Research Ethics Committee HREC/13/SCHN/440
South Australia	· Aboriginal Health Research Ethics Committee 04-14-572 · Women's and Children's Health Network Human Research Ethics Committee HREC/14/WCH/65 · Flinders University SBREC Project OH-00065
Queensland	· The University of Queensland Medical Research Ethics Committee 2014001541 · Children's Health Services Human Research Ethics Committee HREC/14/QRCH/328 · Townsville Hospital and Health Service Human Research Ethics Committee HREC/14/QTHS/209
Northern Territory	· Central Australian Human Research Ethics Committee HREC-14-253 · Human Research Ethics Committee of Northern Territory Department of Health · Menzies School of Health 2014-2214
National	· Department of Health Human Research Ethics Committee 39/2014

Objective 1 – Methods for research with multidisciplinary burns teams

The first objective was to investigate how burns care in Australia is delivered in and from tertiary burns units and what informs the burns care that multidisciplinary burns teams provide.

In order to investigate burns care in tertiary health services, members of multidisciplinary burns teams at six paediatric burns units across Australia were consulted. During on-site consultation and observations, clinicians were asked in semi-structured interviews to provide a description of typical burns care and pathways followed upon presentation of a child requiring burns care. The investigation focused on both structure – the organisation, communication, referral processes, rehabilitation and community outpatient care; and processes – the existence and use of structured care plans, clinical pathways, assessment protocols, rehabilitation prescriptions, and post-discharge management pathways at each site. To identify what informs the care provided, burns teams were asked about their use and application of guidance. To investigate burns care specifically for Aboriginal and Torres Strait Islander children and families, burns team members were asked if they provide different care for Aboriginal and Torres Strait Islander patients.

Recruitment of multidisciplinary burns team members

A purposive recruitment strategy was engaged (Patton 2015). The contact names and respective details of lead burns clinicians from the six tertiary paediatric burns services were obtained from the overarching study. Lead burns clinicians at each site were contacted about the study via phone and/or email and invited to participate. Arrangements for on-site visits were made. Lead burns clinicians were asked for a list of burns team members and corresponding email addresses. Burns team members were invited to participate via email prior to the researcher's visit. Professional information about me, as the key researcher and key study details were provided. Potential participants were able to respond to the researcher individually to make arrangements for an on-site interview at a mutually agreeable time in a private office space. Any other identified members of the burns team were also invited to participate in the study during the researcher's on-site visit.

Consent to participate in research

All participants underwent a formal, written process of consent. Participants were provided with a 'participant information sheet' (Appendix 10) detailing all relevant aspects of the study. Participants were given the opportunity to review information and ask questions. After such, participants were required to sign the applicable consent form (Appendix 11).

Data collection using interviews

Semi structured interviews (Appendix 12) were conducted onsite, audio recorded, transcribed in full by a contracted transcriber, and verified by participants to ensure trustworthiness of data. The verification process was executed via email, whereby participants were emailed their transcripts individually and given three weeks to review. Minor changes were made by five participants. Changes were mostly focused on grammatical errors. Due to the national approach and necessary travel requirements to complete the site visits, week-long visits were made to each site. Participants willing to engage in an interview but unable to during the time of the on-site visit were offered a phone interview at a time that suited. This was the case for two participants. The remaining 74 interviews were face-to-face. Interviews took between 30 and 80 minutes each. The principle of saturation (Patton 2015) was implemented such that when no new information was being obtained interviews at each site ceased. Achieving saturation was complicated by different structures and processes of work across the sites and differing disciplinary perspectives within teams.

Beneficence

The participants in this study may be easily identifiable, due to the small number of specific burns healthcare professionals involved and the information that they provided may be sensitive. Care has been and will continue to be taken so that participants and the sites at which they are employed are not identifiable by the information they provided. This will be the case unless they agreed to be identified. When disseminating information and findings from this research, consideration was and will continue to be made to protect the identity of participants. Participants were informed in the 'participant information sheet' about the potential to be identified in the results of the research even with all identifiers removed.

Data management

All data, including audio recordings have been de-identified and stored in a secure location at Flinders University. All electronic documents are stored on the university's secure central network server. Whilst data have been de-identified, the means still exists to re-identify the individual data sources through a separately created coding system.

Analysis of interview data

Interviews were transcribed verbatim by an external contractor, checked for accuracy by each participant and uploaded to NVivo 11 qualitative analysis software (QSR International). Each transcript was categorised according to interview type (face-to-face or telephone), hospital site, profession, years of experience, gender and cultural training attendance. Data was analysed in two main stages. Firstly, using an inductive thematic method (Patton 2015), data was analysed for description and meaning. The second stage of coding was informed by the theories of decolonisation and cultural safety. Applying Ganma (Pyrch & Castillo 2001) in research processes facilitated multiple theories to come together at the interface for analysis. Data was synthesised further with the theoretical constructs of decolonisation, cultural safety, and ecological modelling. The various stages of the analysis and synthesis of data are now presented in detail.

Stage one coding of interview data

Transcripts were coded in site groups. For each transcript, I read it in its entirety and then re-read the transcript to generate initial codes and develop themes. Themes related to factors that shape burns care, such as systems and structures, and the delivery of burns care, including aspects of processes and procedures. Sub-themes that shape burns care were found to be either system, service, team or individual factors. Some codes also reflected participant values and beliefs. Prior to this, I conducted coding of my reflexive journal, which helped to provide an idea of possible key themes. Supervisor TM also coded two transcripts independently which were discussed together in detail. Specific data, rich in context and having personally challenging content, were identified during this stage and flagged for further consideration in the second stage of analysis. During the course of this analysis process, regular meetings were held with the entire supervisory team to assess and validate coding.

Stage two coding of interview data

In line with interface research methodology (Durie 2005), methods to ensure Indigenous knowledge consideration and inclusion were engaged. As such, contribution was sought for data analysis from Ngara Keeler, an Aboriginal woman external to the main project, yet linked closely through a cultural mentorship role to the main researcher. Ngara has extensive experience in healthcare programs and qualitative research. Consistent with the coming together of Indigenous and Western knowledge, these processes contribute to reliability of data analysis and demonstrate our application of interface research methodology.

Six transcripts were purposely selected for Ngara to analyse in their entirety. The selected transcripts included participants from a mix of jurisdictions, with varying levels of seniority and engaged in different professions. Ngara followed the same analysis process as detailed above. Following this analysis, Ngara and I met in a private space to discuss the outcome of the analysis. Ngara was given the opportunity to present and discuss her overall thoughts of the data (Appendix 13). Themes identified from this discussion were noted. Following this, Ngara and I discussed where our coding was different, and also where Ngara had introduced new codes. Our discussion included such topics as: respect for the role of the Aboriginal/Indigenous liaison officer (A/ILO) and their value in the multi-disciplinary burns team; the definition of the need for Indigenous versus non-Indigenous clinicians; cultural competence; cultural brokerage; cultural healing practices; cultural spiritual beliefs; racism and decisions around discharge. Where our coding was in conflict, Ngara and I discussed in detail the reasons for the coding and in line with the notion of Ganma (Pyrch & Castillo 2001), and worked towards new understandings of the data.

The second time Ngara was engaged in analysis was for the targeted analysis of six purposely selected transcript sections identified during stage data one analysis. This was to enable Ngara to have an opportunity to deliberately look at enhancing understanding around the particular data. The same process was engaged for follow-up discussions between myself and Ngara. This method of shared learning was not primarily to compare and contrast data coding; rather to bring together knowledges. In this context, it was to bring together meanings and concepts that were different, but not false and to look at and talk through implicit biases. We were able to work with one another and be at the interface of knowledges. Throughout this process I consulted with the supervisory team on how to incorporate new ideas into a logical reflection of my overall findings that embodied the principles of gamma.

Synthesis of interview data

The above analysis method resulted in a large number of codes. Further synthesis of data using a decolonising lens (Smith 2012) resulted in the identification of two major findings: factors that inform burns care and the provision of different care for Aboriginal and Torres Strait Islander children and families. A deductive method (Patton 2015) was used to identify those nuances that facilitate culturally safe burns care, and was a deliberate method to understand how the principles inform burns care for Aboriginal and Torres Strait Islander children and families. See Table 8 in the following chapter for a diagrammatic representation of the major findings and resultant main concepts identified as the result of further synthesis of data.

Ecological modelling of interview data

To translate and apply initial content findings for use in health service delivery, an ecological framework (Reilly, Cincotta, Doyle et al. 2011) informed further examination of the subsection of coded data about those things that inform burns care. While the broad factors identified to shape burns care already reflected a layered construct including system, service, team or individual factors, this part of the analysis enabled identification of those things that inform burns care as the outcome of interactions among many factors across multiple levels. The ecological framework also provided a space to actualise the significant influence of policy and systems on healthcare. This is important given the negative consequences to health outcomes past and current Australian policy has on Aboriginal and Torres Strait Islander peoples (Couzos & Murray 2008). The ecological framework also enabled a more holistic approach, well aligned to those connections Aboriginal and Torres Strait Islander peoples have to community, Country and culture that are interdependent and broader than oneself (Durie 2005). Where Indigenous knowledge is situated as dynamic and relational (Durie 2005) the ecological framework enabled data to be considered and presented in context and across different levels of the healthcare system from a system level through to the individual level. The ecological modelling is evident in the manuscript presenting data on what informs care in chapter eight.

Deconstruction and reconstruction of interview data

While the data was deconstructed into individual codes in stage one and stage two of the analysis process, careful consideration was made as an ongoing process to reconstruct the data. From the processes in stage one and two, data was broken into parts with relevant examples drawn. The reconstruction process provided an opportunity to enhance understanding of the findings by putting it back together in a different way to expose deeper meanings. Furthermore and in-line with Indigenous knowledges, ways of knowing, being and doing are as a whole and in relation to each other as opposed to single parts (Moreton-Robinson & Walter 2009). This was an iterative process that occurred as a result of my evolving understandings of the data, through conducting the interviews and linking them across the different sites and to my own experiences and coding and re-coding the data with Ngara.

Concluding statement for analysis

Regular discussions were held throughout the entire analysis process with the investigative team, including with supervisor TM (a public health medical officer of Waljen descent) and my non-Indigenous supervisors. These discussions informed and validated the data analysis processes at each stage. Consistent with the coming together of Indigenous and Western knowledge, these processes further contribute to the reliability of data analysis and also demonstrate my application of interface research methodology.

Chapter summary

In this chapter I have described the methods engaged to conduct ethical research at the interface of knowledges for the project overall. Framed by interface methodology and genuine engagement with Indigenous conceptualisation of information, a holistic data analysis method has been described. This is akin with holistic approaches to health and healing. The aforementioned analysis method resulted in a large number of codes that were impractical to report. As such, the next chapter (chapter seven) provides only a summary of the themes and sub-themes found to shape burns care and aspects of the delivery of burns care. The two chapters following this one (chapters eight and nine) present the specific findings following theoretical synthesis of data and are presented in manuscript form. Chapter 10 presents the methods for addressing objective two and relates to the patient journey mapping.

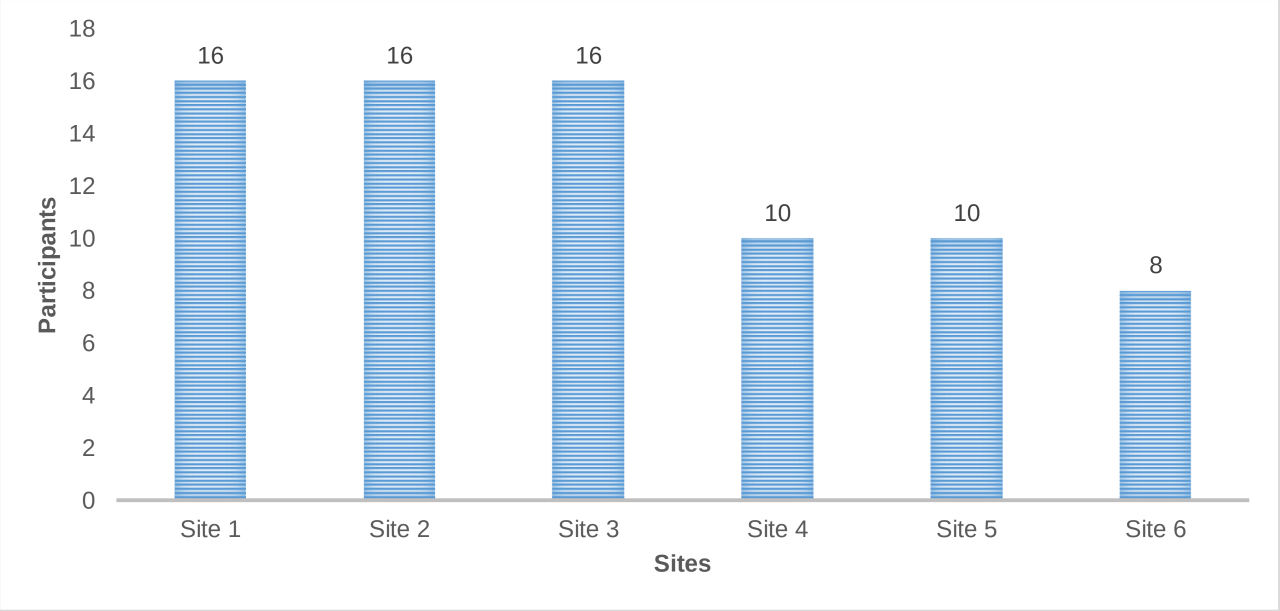
CHAPTER 7 – A descriptive summary of the main findings regarding the structure and delivery of burns care

In this chapter, I present the major findings from the analysis of 76 semi-structured interviews with burns team members about burns care for children and families in Australia. Analysis of interviews resulted in a large amount of data that was impractical to report on in its entirety in this thesis. The two major themes, factors shaping burns care and the delivery of burns care are reported on in this chapter. Four main sub-themes were found to shape burns care. These include the healthcare system, healthcare service, multidisciplinary burns teams and individual burns team members. Three main sub-themes were found regarding the delivery of burns care. These include the types of care, process of care and delivery of care. These themes were further analysed into sub-categories. Findings were synthesised using a decolonising lens as described in chapter six. The resultant synthesis is presented in chapters eight (factors informing burns care) and nine (provision of different care). These chapters contain manuscripts that have been submitted for publication in peer review journals.

Overview of the findings

I interviewed 76 members of the multi-disciplinary burns team over a six-month period in late 2016 to early 2017 at six tertiary hospital sites across Australia (Figure 3). Four of the sites were paediatric specific services and all had a dedicated multi-disciplinary burns team.

Figure 3 - Number of participants recruited per site



Of those interviewed, 57 were female, and a high proportion of participants were allied health professionals (36%) (Figure 4). Allied health staff included social workers, occupational therapists, physiotherapists, dieticians and play therapists. Only one site had representation from all six professions. Three sites had representation from five professions, and the remaining two sites had representation from four professions (Table 7).

Figure 4 - Number of participants by profession and gender

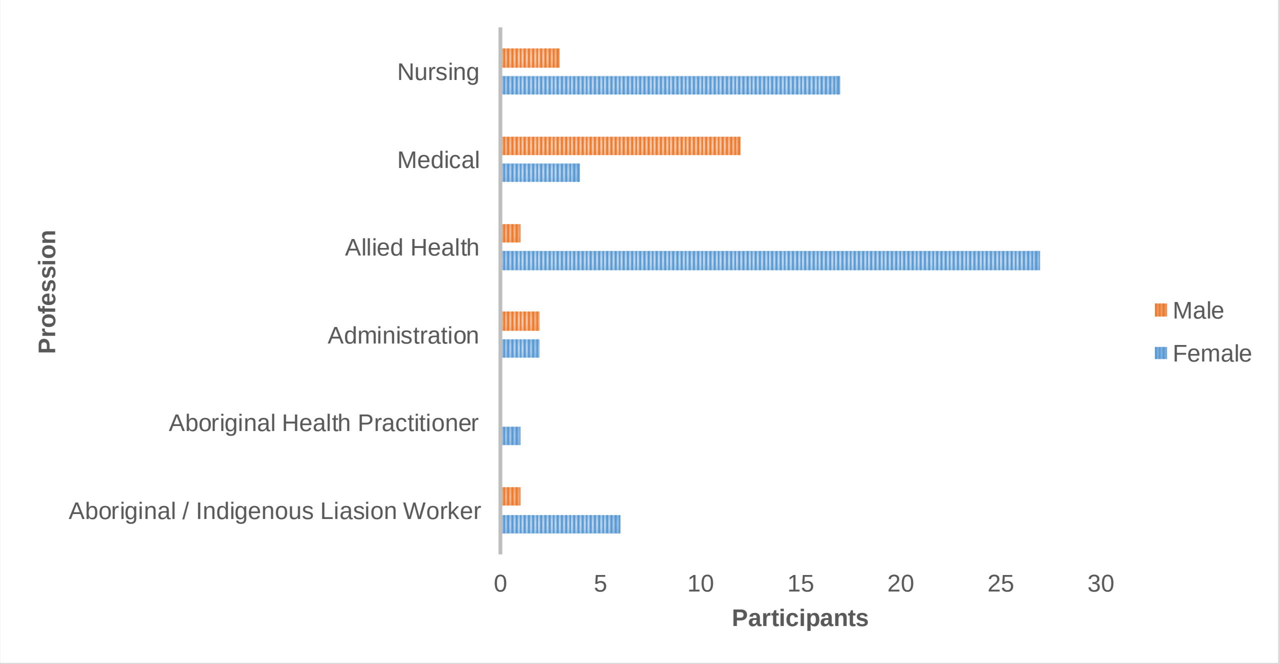


Table 7 - Number of participants by profession and site

	Nursing	Aboriginal health practitioner	Medical	Allied health	Aboriginal / Indigenous liaison officer	Administrative
Site 1	4	-	3	6	3	-
Site 2	5	-	4	6	-	1
Site 3	4	-	4	6	1	1
Site 4	2	1	2	4	1	-
Site 5	2	-	2	4	1	1
Site 6	3	-	1	2	1	1

Participants were asked to describe the delivery of burns care at the health service site at which they are employed. Thematic content analysis of data identified two major themes: factors shaping burns care and delivery of burns care. Sub-themes and sub-categories were also identified in this analysis process (Table 8).

Sub-themes that shape burns care included: 1. the healthcare system; 2. the healthcare service; 3. the multi-disciplinary burns team, and 4. the individual burns team member. Participants described the components of the healthcare system shaping burns care relate to structure, funding and policy. Data identified that burns care is shaped at the service level through meeting indicators of quality, mostly directed at clinical measures. The identification of Indigenous status was a healthcare service factor also shaping burns care. Multi-disciplinary burns team composition, leadership and professional relationships also shape care. Communication within teams is enhanced through multi-disciplinary meetings and influenced by senior clinicians. Dedicated inclusion of some professions, for example the Aboriginal/Indigenous Liaison Officer (A/ILO) in burns care teams is not systematic. Burns care is shaped by individual burns team members’ skill mix and experience. Their competency, including cultural competency and perceptions of cultural safety, also shapes burns care.

Sub-themes regarding the delivery of burns care included: 1. the type of care; 2. the processes of care, and 3. the delivery of care. The three main types of burns care include clinical care, holistic care and follow-up care. Admission into the burns team for care was based on meeting specific criteria and following established processes. Other care processes included telehealth, care plans and referrals, including internal and external referral pathways, discharge decisions and processes. The delivery of burns care was impacted by clinicians’ perception of families’ compliance and non-compliance with care, client-healthcare professional relationships and by the work of social workers.

Table 8 - Findings from thematic analysis

Major themes	Sub-themes	Categories
1. Factors shaping burns care	1.1 The healthcare system	n/a
	1.2 The healthcare service	1.2.1 Identification
		1.2.2 Quality indicators
	1.3 The multi-disciplinary burns team	1.3.1 Composition
		1.3.2 Leadership
		1.3.3 Professional relationships
		1.3.4 Team communication
	1.4 The individual burns team member	1.4.1 Cultural competency
		1.4.2 Cultural safety
		1.4.3 Family communication
2. Delivery of burns care	2.1 Type of care	2.1.1 Clinical care
		2.1.2 Holistic care
		2.1.3 Follow-up care
	2.2. Processes of care	2.2.1 Admission
		2.2.2 Telehealth
		2.2.3 Care planning
		2.2.4 Referrals
		2.2.5 Discharge
	2.3 Delivery of care	2.3.1 Compliance
		2.3.2 Relationships with families
		2.3.3 Social worker

I now present a summary of each of the sub-themes found to shape burns care for children across Australia. This is followed by a summary of the sub-themes regarding the delivery of burns care. Examples of participant quotes are used to illustrate the findings. As is usual in qualitative research, data will be presented using descriptive language and will not be quantified (Patton 2015).

Major Theme 1: Factors shaping burns care

<u>Sub-theme 1.1 – The healthcare system</u>

A small number of participants referred directly to the healthcare system, including describing service provision area, funding, structure and policy as shaping burns care. One site was described by participants as being part of a statewide network of hospitals that provides specialist burns care to children. For three other sites, participants described their respective sites as stand-alone state-wide specialist paediatric burns services within their corresponding jurisdiction's health system. Two of the other smaller sites described their burns care as being for both paediatric and adult patients and part of the larger tertiary health service for their jurisdiction. More broadly, the states' health system *'mission statements, policy documentation, [and] core values' (2.14)* imply far-reaching application across the health service, and subsequently shape the health services and burns care. Data identified state-based health funding resourced the provision of burns services (6.07, 1.06), along with activity based funding (5.03, 5.04). When talking about the availability of resources for burns care, one medical participant said:

> *'I think also the set-up of the hospital, the hospital treats burns seriously and provides as many resources as is needed in order to run a good burns unit, it's certainly outcome focussed rather than sort of cost or resource focussed and that enables the unit to do whatever it takes to get the best outcome (1.14).*

Resources for specialised garments was discussed by many allied health participants due to their expense, but were never mentioned as not being made available to patients. The state-wide integrated medical record system funded by the state government supports the provision of follow-up and rehabilitative care for burns: therefore *'…for some it's easy to see there's tracking because of the state-wide integrated medical records but some towns and cities aren't on, so not every place is on the records'* (6.06).

Sub-theme 1.2 – The healthcare service

Participants reported aspects of the healthcare service as shaping burns care. This included admission to the health service, identification of Indigenous status and service facilities and requirements to meet certain health service indicators of quality.

1.2.1 Identification of Indigenous status

When discussing the admission process, many participants talked about the identification of Indigenous status. Most said that it *'should be identified when they're admitted so that's a requirement that they're supposed to be asked'* (2.16). This was supported by another participant who said it was *'yeah mandatory…but even though I have observed sometimes emergency department have missed it and if later I find they are Aboriginal I can change it, I do that when I find a couple of them'* (2.01). The information is stored in IT systems (6.06, 4.03, 4.07, 4.02) and patient files (2.13, 4.02, 6.06, 4.02).

1.2.2 Quality indicators

Participants reported making decisions about aspects of burns care based on quality indicators. These included such things as time for referral and assessment, surgical intervention and follow-up care and referral to allied health services. Quality indicators mostly correlated with time and severity of burns injury. The ANZBA guidelines were referred to frequently by the participants. Patient perspective and feedback on the delivery of care was absent.

Quality indicators for referral to allied health services varied across the sites. Referrals included five different healthcare professions within the burns team. These included dietetics, social work, pain therapy, occupational therapy and physiotherapy. For example, if a burn injury is *'over ten percent and they have burns that involve the ability to feed'* (1.08) referral to dietetics is required, and *'generally we would see them within twenty-four hours from referral'* (1.08). In terms of pain, *'…significant burns that require long acting analgesia'* (1.11) are required to be seen by the pain therapy team within the first 12 hours of admission (1.11). Referral to and assessment by an occupational therapist for all burns is *'…within forty-eight hours of admission and we just need to document that we've done a review'* (5.06). This was in line with the ANZBA Allied Health guidelines (5.06). Referral to physiotherapy was reported similarly as referral to occupational therapy – a blanket referral and assessment but within 24 hours (2.09, 2.13, 1.13, 2.05). However, one medical consultant said:

> *…we're not slaves to the criteria as such, possibly we need to tighten up on that a little bit more ourselves. Again, it's a referral system but it's mostly word by mouth, it's a small unit, you know they arrive, they get seen and that's the way it goes, we don't sort of go, oh my gosh they haven't been seen, it's twenty-six hours, we need to tick off the box, you need to come up here now. It's more of a pragmatic approach… (5.05).*

Many participants reported that all children with a burns injury are required to be seen by the social work team at least once. This is via a blanket referral process (1.01, 2.07, 2.16, 6.08). Furthermore, patients are required to be seen within 24 hours of admission at the tertiary site (6.08, 2.16). *'At the point within twenty-four hours of a patient presenting at [site], under the ANZBA guidelines, 'social work' need to see the family within twenty-four hours of that admission'* (6.08). This was sometimes not the case for burns presentations over the weekend (2.16) and was not stated as an indicator of quality at all sites.

Some of the A/ILO participants talked about how they are notified of Aboriginal and Torres Strait Islander patients in the hospital through lists and how it is mandatory to see patients. *'If they're an inpatient and they're on our list, yes…we have to go and make sure that they're okay, the patient and the escort'* (1.05). However, *'if they're not identified on the system as Aboriginal they probably will be missed. Unless they request for an ALO to be present'* (1.05).

Some participants (5.03, 5.04) from the same site talked about indicators and 'trigger points' for surgical decisions. *'We always re-assess at forty-eight hours so that then we can re-assess the patient and re-assess the wound…and if at that point it's looking like it needs surgery I'll send that on to the consultant'* (5.03). In addition, *'…there are trigger points around the seven to ten day mark, what is left unhealed because we don't want anything left unhealed by that timeframe and of course that's a really high KPI but we drive that hard'* (5.04). Notwithstanding, *'it is a very complex decision-making matrix'* (5.04). Another indicator of quality for the same service is regarding healing and scars. *'If you healed within ten to fourteen days we do a six week scar check…we're doing [this check] on a thing called video-call which is a phone app'* (5.04).

Participants also spoke about meeting key performance indicators and data collection, auditing and quality improvement activities. One participant said about meeting key performance indicators that *'it's a bit difficult…because a lot of our inpatients are toddlers and they are often in and out in under twenty-four hours'* (2.13). For another site, *'the protocol to get people into theatre within six hours possibly isn't being achieved all of the time'* (4.10) and was further explained by another participant from the same site to be a result of *'…protocols around bed management and escalation phases that we go through and bed block etcetera'* (4.03). Data collection as it relates to quality improvement and benchmarking was described by a small number of participants (2.08, 4.09, 2.09). One site talked extensively about their audit meeting, saying it is a meeting held once a month with the whole team and was an *'audit of our activity and complications basically'* (2.08). Data collected was reported to be for quality improvement, however was without patient feedback, for which the participant said '*there should be [patient feedback] but no we don't and I think that's seriously lacking'* (2.08). This was supported by another participant who stated that they are *'interested in…the quality of the service in terms of from a user's point of view, measured by compliance and turning up to clinic appointments'* (4.09). Another medical participant said *'a lot of the stuff we do doesn't really have much of a guideline that you can benchmark…what is quality care and how we compare ourselves versus the rest of the nation and other units'* (4.09).

Sub-theme 1.3 – The multi-disciplinary burns team

Much of the data related to the multi-disciplinary burns team was regarding a participant's description of the configuration of burns teams and their functionality. Such things included the composition, skills and organisation of the burns team, along with relationships, leadership and communication within and between members of the team.

1.3.1 Burns team composition

All of the participants were members of multi-disciplinary burns teams consisting of a variety of professions, including broadly medical, nursing and allied health. There was little difference in composition across the burns teams. One team engaged an anaesthetist and play therapist in their outpatient clinic. Another engaged a part-time Aboriginal Health Practitioner in their team, and in one team, nurse practitioners were employed. In terms of medical staff, a mix of general surgical, paediatric and plastic specialties were part of the burns teams. The resultant mix of these specialty areas was described as making some services unique (2.07, 1.06, 1.14).

The data showed inconsistency of inclusion of and contribution to burns care by occupational therapy and physiotherapy. For one burns team in particular, physiotherapists lead the scar and mobility component of burns care (2.07, 2.11, 2.13) and occupational therapy is more or less not involved. *'We have had OTs for very brief periods over the years but X has disagreed with their* *philosophy and I mean fundamentally physios and OTs have a different kind of paradigm when you're dealing with things'* (2.13). For another burns team, scar and mobility burns care is predominantly performed by the occupational therapists. *'Occupational therapists cover a lot of things that in other services physios might do which is fine, we don't have any territory wars here'* (4.08).

1.3.2 Leadership within the burns team

Data identified differences in team leadership between units, along with differences of opinions about leadership within teams. Leadership concerned 'organising' care. Most predominantly, data identified that there is a lead registered nurse who provides leadership and is the main organiser of burns care (1.06, 1.07, 1.13, 2.03, 2.08, 4.03, 4.07, 4.09, 4.10, 5.03, 5.05). In one instance a medical participant said the team was co-led: *'in terms of the team I guess the way we run it is the nurse unit manager of the burns unit and I tend to provide the leadership roles across the spectrum of the team'* (2.08). This was reported similarly for another site (1.06). For one smaller service, two participants (medical and occupational therapist), reported the occupational therapist provides the main team leadership (3.04, 3.1).

1.3.3 Professional relationships within burns care teams

Good professional relationships between members of the burns team were considered important. Teamwork (5.03, 3.14) and respect for each other's contribution to multidisciplinary care are key (5.04, 5.06, 6.03). This was mostly about effective and efficient delivery of burns care and improving client care. Longevity and subsequent experience within burns team contributes to and has resulted in the reported good professional relationships amongst burns team members (1.12, 3.11, 6.03). For example, when talking about team relationships, one allied health participant said *'…we've known each other for a long time and not necessarily always through burns…so there's that experience about each other that has underpinned [our good relationships]*' (6.03).

1.3.4 Communication within burns teams

Almost all participants reported various aspects of communication as either required in their role or important, especially in relation to the functionality and efficiency of multi-disciplinary team care, and client outcomes. Mechanisms of communication engaged in were both formal and informal. Formal mechanisms included scheduled multi-disciplinary team meetings, case conferences, specialty meetings, ward rounds and morning meetings. Informal communication between team members happens *'every day, all day every day'* (1.01) with communication between medical staff frequently *'…via text and email'* (2.07). Sometimes this meant communication was not always documented (1.01, 2.02, 6.03, 6.08).

Multi-disciplinary team meetings were mostly reported as happening weekly with a range of team members attending. *'So it's the medical team, myself, allied health staff and plus or minus some other allied health members of the team like dietician, speech therapy, speech pathologist, infectious diseases, APS [acute pain service], those people if it's appropriate they will all attend'* (1.01). These meetings provide an opportunity to *'discuss specific patient needs and formulate a coherent plan, so that's really essential for our inpatients in particular but also in terms of the long term functioning of the unit that's really important as well'* (1.07). The importance of the meetings was echoed by the majority of participants who described them. However, inclusion of A/ILO in these meetings was not reported by participants, nor clear in the data. One A/ILO said that *'…going to those meetings, there's been times where you just say your little bit and then that's it they sort of forget that you're sitting there you know and I don't think that's right'* (1.03). She went on to say: *'…they need to sit down and listen and involve us…not just bring us in and get the little bit of information that they want and then forget that we're sitting there'* (1.03).

Sub-theme 1.4 – The individual burns team member

The large majority of participants had been involved in burns care for more than five years. Many reported greater than 10 years of experience in burns care. Participants were not asked about their formal qualifications, however reported on their attendance at cultural awareness training and their knowledge of cultural safety. Whilst data about cultural awareness training and cultural safety are included here, they do not relate specifically to burns care. Data also identified individual communication techniques employed by burns care team members when working with patients and families.

1.4.1 Cultural competency in burns team

Almost all participants, 92% of those asked (62/76), had attended cultural awareness training (Figure 4) at some stage in their professional career in health. Most participants reported it as being mandatory. Of those that had not attended training (5/62), three were medical participants and two (nursing and allied health) had been employed for less than one year and reported not having completed all mandatory training.

1.4.2 Culturally safe burns care

In some interviews, participants discussed and used the words 'cultural safety', however when asked, not all participants knew what cultural safety meant. This was not explored nor explained. Four participants, all from the same site, said unequivocally that they had not heard of the term 'cultural safety' and did not know what it meant (1.01, 1.11, 1.13, 1.14). Another participant from the same site said they can't remember hearing the term, but could interpret the term as being about respect (1.12). One participant, who also had not heard of the term 'cultural safety', interpreted it as: *'I suppose it's mainly about being respectful and making them feel safe within this environment because it can be very challenging'* (5.06). Another participant said they had heard of the term in the cultural awareness training they had attended, however said *'that's probably something that I'd like to learn a bit more on, I think that's probably something that I could probably practice a lot better, just understanding it a lot more as well'* (2.15).

Seven participants described cultural safety as considering kinship (3.09), the importance of family (3.09), language (3.09, 5.07), religion (1.09), beliefs (5.07) and appropriate eye contact (1.09, 1.10). Being respectful (1.09, 4.07), sensitive to what a person believes in (5.07) and giving more choices (1.10) were examples of being culturally safe. The Aboriginal Health Practitioner participant responded to the question about cultural safety by saying *'…cultural safety is when this organisation gets to the point of writing into our paperwork the cultural considerations for patients'* (4.01).

1.4.3 Communication by burns teams with families

Data indicated participants consider and use different communication techniques to enhance understanding about burns care with children and families, especially in relation to not being able to understand English (5.07, 2.05). Having empathy (3.13), spending time (2.07), being nice (2.07), speaking at an appropriate level (2.07), having consistency of messages between different burns team members (3.09), explaining in detail (5.02, 6.02), educating (6.20), using open-ended questions (5.03) and using stories (6.02) are all techniques reported to improve patient and family understanding. One participant said that small pieces of information frequently helps with increasing understanding (3.15). A good understanding of the burns care by caregivers was described by one participant as resulting in reduced anxiety (6.02). In terms of communication about follow-up care requirements, one nurse said they try and *'…make it as simplistic as possible and write things down so when you get home you can sit down and re-look at it and say, that's what she said, she's written it there…'* (6.02). One participant thought communication about length of stay could be better because *'then mum or aunty or grandma or dad, whoever has come with, is left scrambling trying to make care arrangements for the rest of their family in the community' (3.10).*

Major Theme 2: Delivery of burns care

<u>Sub-theme 2.1 – Type of care</u>

2.1.1 Clinical care

All participants described the provision of clinical care, either their involvement in clinical care or how the multi-disciplinary team they work with delivers clinical care. Topics mostly concerned clinical assessment, clinical care decisions, early intervention, expert care and triage. A smaller number of participants talked about a lack of clinical expertise and not delivering ideal burns care.

The initial clinical assessment described by predominantly nursing and medical participants was mostly about determining total burn surface area (TBSA). '*We do an initial assessment of the burn wound so we basically do the TBSA assessment, mechanism, any first aid and the presence of sensation in there*' (4.02). Many participants in senior medical and nursing positions described using photos via the site's telehealth service to make the initial assessment. Some participants reported that initial assessments can be inaccurate, especially with children who have darker skin pigmentation (3.12, 4.09, 3.10), and sometimes about more than TBSA (1.07). One medical participant said:

> *…we'll try and get an understanding of what the family structure is and what the household in which this child lives is in order to make decisions. And also families which might be at risk for various reasons whether they be nutritional reasons, adequacy of follow-up, return for visit (1.07).*

The initial assessment was different for social work (6.08, 2.16). A physiotherapist said they make '*that [first] assessment during the dressing change...to see really the joints that are affected and how quickly the effect can be detrimental*' (5.09).

Clinical care decisions were predominantly reported by medical participants and by a few senior nursing and allied health participants. Clinical decisions were described as being made mostly by medical staff, who take full responsibility, or by a combination of professions. Medical staff in burns team were reported as making the majority of the clinical decisions. This was reported mostly by medical participants (3.04, 2.14, 3.03, 5.05, 3.06, 4.09). Decisions were based primarily around the need for surgery. Care was deemed to be consultant-led and delivered (2.08, 3.06, 3.09, 3.13, 6.02) with one medical participant stating: *'the consultant is responsible for all of it'* (2.08). One medical participant said medical staff make all of the clinical decisions, but also mentioned some decisions are made in consultation.

> *We're responsible for all the decisions, we make the majority of them either in consultation with the CNC, with our junior medical staff or in isolation with other medical teams but ultimately the responsibility is with us. It's very strong medical and nursing leadership here (5.05).*

Other medical participants (1.06, 1.07, 1.14, 2.08, 5.04) described team-based decision-making. When talking about making decisions about surgical grafting, one medical participant said decisions are made '*in consultation with nurse practitioner, burns fellow and also run past the consultant'* (2.08). For outpatient care specifically, a medical participant said *'I become involved in outpatient care when our nurse feels that that patient needs additional input'* (1.07). In relation to telehealth outpatient care, the nurse practitioner at one site said *'so I am the one that oversees and flags that they potentially need to come here and need to have something done'* (2.03).

Participants said that burns care is a specialty area, requiring specialist skill sets (2.07, 3.11, 4.09) and experienced clinicians who contribute to the team functionality (1.14). Burns team members are often asked to provide their expert care in different departments at the tertiary site, usually in the emergency department (6.05). Accessing this expertise was reported as difficult for those families living outside of the metropolitan area (2.05). This was echoed by another medical participant and relates to both acute and follow-up care (2.07).

Expert guidance was used to inform and guide burns care. An ICU medical participant said *'we really rely on them to direct us to what the best way is to look after the actual burn for the child'* (3.13). Another medical participant said they use the expertise of the team to provide care (6.07). A psychologist said they work with the A/ILO if '*there's some difficulties with engagement or building a therapeutic relationship…we [often] work with other people that might have more expertise'* (5.08).

Two participants described patients not having access to the best burns care. One was in reference to pain management post discharge (1.11). *'We certainly don't run a service that probably delivers that ideal care for chronic pain that may occur'* (1.11). This participant suggested that the tertiary health service needs to resource a chronic pain clinic for management of patients with pain to improve quality of life. The case of not having access to the best care was regarding rehabilitation and follow-up care, whereby one senior nurse said: '*It's really hit and miss about who gets well supported care and who doesn't if I was being really, really honest it really does, there's no consistent approach to it at all'* (4.03). Factors impacting this as described by the participant were the service's physical facilities and the lack of skills and knowledge of the healthcare professionals providing the rehabilitation care. '*They are generalists and don't know what to do with burns*' (4.03).

2.1.2 Holistic care

Two participants alluded to holistic care, however the word 'holistic' was not actually used. One said that at *'…the other weekly meeting that's just nursing and allied health…we can talk about things that the doctors don't necessarily want to talk about and…we can then focus on the whole of the kid and focus on the family'* (6.03). The other said they don't provide holistic care. *'I don't think anyone looks after the mind very well…I'd like to see them [psychology] here all the time, I think they should be with every single admission that comes through'* (6.05). Accessibility to psychological services for burns patients differed between the sites.

2.1.3 Follow-up care

A large amount of data resulted from participants' descriptions regarding the care of a burns injury once a child and family had been discharged from the tertiary site. The data was summarised by one participant who said: '...follow-up care for a burns injury post-discharge can be complex and time-intensive. Some families struggle with this and it can be something that is over a long, long time. Many families miss appointments and we [the burns team] try to keep them engaged in care as best we can' (5.09).

Participants described how appointments for follow-up care are made by a mix of clinical and administrative staff. The day of the week that appointments are made is often a direct result of severity of burn and availability of medical staff (1.15, 3.01). For example, for one site a participant said:

> *Monday, Wednesday and Friday specifically in the morning is when both the paediatric outreach nurses and the occupational therapists are available to do joint appointments…and if they need to call on one of the consultants or any of the registrars to come down and review the patient while they're here, it's usually in the mornings is the best time to get them to come in and do that (3.01).*

However, data showed the structure and set-up of out-patient clinics for providing follow-up care differed across all sites. This was in terms of professional involvement and clinic hours. Many participants reported trying to arrange joint appointments (1.12, 1.13, 3.08, 3.14, 5.05) to reduce unnecessary strain on children and families. This was even in regards to other areas of care, for example ENT (5.05).

'The loss to follow up is huge and they're [parents are] very well intentioned and really want to do the right thing but the trouble is once they're home it can be really challenging to organise to get back' (2.13). Many of the participants describe attempting to follow-up with caregivers following missed appointments. Sometimes these families are sent another appointment card without consultation (1.02, 1.15, 1.14) and at other sites, phone calls are made first. Sometimes the medical staff review the file and make a decision regarding care (1.10, 1.02). Following multiple missed appointments and where follow-up care is deemed necessary upon medical review, social workers would be engaged (1.02, 5.01, 2.04, 2.05, 6.07, 6.02). *'Any patient who doesn't turn up for an appointment, we'll review that situation and give another appointment and if they keep failing to attend then we get the social worker involved' (*6.07). A social worker responded by saying they:

> *'…would go through FACS because quite often they may be known within the community…I might even contact the local AMS if there is one in the first instance because they generally would know the population, but they're not always in all communities which is a problem' (2.16).*

This was reported similarly by another social worker (2.15). To find those children and families that do require care, one participant said they go as far as to ring *'…the public phone that's standing in the community'* (5.03). For transient families, one participant said they have *'called Aboriginal Health Services, and they've said yeah sure I'll go around'* (1.13).

Sub-theme 2.2 – Processes of burns care

2.2.1 Admission for burns care

Participants across sites reported similar processes and requirements for the admission of a child into the care of the burns team. Admission was for out-patient care, in-patient care or care via telehealth. Admission via the emergency department was common; however for two sites, first contact with the burns team was more often than not via telehealth. This was predominantly for smaller burns. Admission into the burns team for care was also via the site's outpatient burns service. Occasionally, children and families are transferred from one tertiary hospital directly into the care of the burns team (4.03). Children are also transferred from other health service sites.

> *There are clear guidelines for transfer, the transfer of children with burns injury, as you know we go by the ANZBA or the EMSB guidelines, transfer guidelines as well as the referral guidelines, so I get referrals from GPs, from EDs, from wards here for patients and for consultation and for transfer. As I said, on those days when one of the paediatric surgical consultants are on-call everything goes through me and so the liaising for transfer would go through me and NETS (Neonatal Emergency Transport Service) if needed and the receiving hospital as well (2.14).*

Specific site criteria, or criteria referred to as the 'ANZBA' (Australia and New Zealand Burns Association), guided decisions for admission into the burns teams for care. For most sites, protocols for the care of a burns injury exist for emergency staff to follow, with emergency staff referring to the site's burns team as required (1.09). However, many participants reported that a member of the burns team would often assist with the assessment of the burn in the emergency unit.

> *So they'll come to us via department of emergency generally and then they come up to the ward, they'll be seen on the ward by the team or seen in emergency by the team, the doctor and the nursing staff. I suppose they're seen downstairs by a registrar and if emergency aren't confident with the burn they'll then ask one of my staff from the ward to go down there and look after the burn down there (6.05).*

One participant reported that only occasionally a burns injury is treated and discharged from the emergency department without involvement of the burns team (3.03). However, three participants from the same site reported they occasionally have difficulties with their emergency department not providing what they consider to be the best burns care (3.04, 3.09, 3.11).

2.2.2 Telehealth

Participants across all sites described their service's telehealth facilities and processes in detail. Participants who spoke about telehealth said the reason for developing these services were mostly to facilitate the provision of follow-up care.

> *Initially it started to facilitate discharge planning to stop people coming back and forth, it's very expensive to bring people for appointments, so the main reason was actually not necessarily to keep people at home but to keep people in the community so you didn't have to travel all the way up for them to say to me, oh yeah I'm happy with my scar (5.05).*

Telehealth services have reportedly evolved, and participants reported nurse practitioners, clinical nurses, allied health and medical staff monitor the various digital imaging systems. The telehealth service for two units is changing whereby caregivers are now sending through photos where it was initially set up for use by healthcare professionals (2.05, 5.03). Static images are mostly emailed to dedicated services *'used acutely from a consultation, almost diagnostic, purpose in that initial phase'* (2.05). Participants reported saving people's time and improved economic efficiencies as benefits in the use of telehealth. '*We will co-manage kids in their local health districts to reduce that travel time and disruption on family life and everything else that goes with it'* (2.03). Telehealth has also reportedly resulted in improved access to specialist care because *'…every patient no matter where they're burnt in [this state] gets optimal treatment with specialist input early, that's important because everyone deserves that'* (5.03). For one site, 'live video-streaming' clinics are supported by a separate telehealth department at the site who also ensures functionality of IT equipment and connections (5.01). In regards to 'live video-streaming' for one site as reported by a senior clinician:

> *…we feel that sight, touch and involvement is not possible to the level at which we practice it with telehealth. We follow up pictures in the acute burn, but we don't run telehealth clinics…I don't think it's useful in terms of long term follow-up just because I mean the emotional side of it is really seriously lacking in telehealth, you can't have any sort of nuance response to the emotional, social or even physical issues (2.08).*

2.2.3 Care planning

Data indicated that case conferences, case management, continuity of care and coordination of care, are important aspects in planning burns care. In ward rounds, one nurse said:

> *…we're talking about practical things…what does the doctor and the nurse think that the dressing should be, does the occupational therapist think it needs a splint, are we thinking it might need a graft, when do we think it should be done. It's just an immediate treatment plan to get you through to the next three days usually (6.02).*

Another participant said that case conferences are*'…more I suppose, specific',*(1.12) and are in addition to ward round and the weekly burns meetings described above in team communication. This type of case conference can be requested by anyone in the team and *'the health professionals who are deemed necessary would be invited to attend that to contribute'* (1.12).

Two participants (2.07, 2.11) from the same service said that consistency in planning was very important for patient and family understanding and adherence to care regimes, and a further three participants (2.10, 3.11, 6.07) from different services spoke directly about the importance of continuity when planning care. Six participants (2.15, 4.01, 4.03, 4.09, 5.03, 6.02) spoke directly about case management in planning and facilitating burns care. Case management is when *'all the team members come in at once, discuss the burn, what we all think is a good plan, dressing, occupational therapy, physio, what's needed, when to return'* (6.02). The registered nurses were reported as the main facilitators and pivotal to case management as described by one medical participant (4.09). Co-ordination of care was reported by participant as the aim of case conferences and the result of case management (1.10,1.12, 1.13, 2.05, 2.16).

2.2.4 Referrals

Data regarding referrals into the burns team related to both external and internal referrals. Burns teams receive referrals from outside of their tertiary site, mostly from other healthcare professionals. With the increase in the use of telehealth, participants reported some referrals, in the form of photos, coming from parents (2.05, 5.03). Various referral criteria exist. Most participants reported the ANZBA guidelines. Data also identified referrals from the burns team to community services for follow-up care and rehabilitation.

Data identified internal referral between members of the burns team varied for professions and between burns team. One term used and referred to by many participants was ‘blanket’ referral.

> *We have blanket referrals pretty much to social work, dietician, physio, every single person of the allied health team gets a standard consultation by all of those multi-disciplinary team members so we don't have to physically put in an online referral from a doctor and say physio can you come and see this patient, they're all blanket referrals (2.05).*

It was not a ‘blanket’ or mandatory referral to these allied health professional across all sites. For example:

> *…so all burns patients are referred to our social worker, our OT and our physio. And then from there whether we will refer onto other services like A/ILO or our music therapist, our dieticians and all of that, they're not all mandatory (6.03).*

2.2.5 Discharge

Data as a whole indicated that clinicians want the best outcomes for their patients and families and base decisions around discharge on this desire. Many participants talked about discharge from tertiary care, and how hard it can be, especially for families who live outside of the direct metropolitan area. As an example, one participant said:

> *… they don't necessarily like to make it known how hard it's going to be for them at home and how hard it's going to be for them to get back because I get the impression that they're worried that we won't let them go and so they do tend to downplay that and say it's okay (2.13).*

For complex cases, extensive planning is required prior to discharge (2.08). One site has a specific health service discharge team who do this (5.02). It was reported that occasionally there is a lack of knowledge about planning for discharge by junior medical staff, or medical staff not working solely or frequently with the burns team. This was reported by three participants (4.06, 4.03, 4.09) from the same site and was mostly about arrangements being made (or not) for access to follow-up care.

Decisions by members of the burns team regarding discharge, usually the medical staff, senior burns nurse or occupational therapist, varied. More often than not, a decision to discharge a patient from care was based on geography and level of access to required care. Consideration of a safe home environment, stage of wound healing, Aboriginality and family capacity also contributed to decisions around discharge.

In relation to discharge decisions based on geography and access to burns care, one participant said they *'…always check if they're a remote patient to be honest because so far as our care and discharge planning goes, that's a big impactor'* (4.08). This was closely echoed by other participants (1.01, 5.05). Participants (1.07, 2.14, 6.07, 6.03) reported keeping children and families in longer if they were from a remote area - a thought also echoed by other participants (2.14, 6.07).

> *I think that I do notice that we tend to keep Indigenous children in for a little bit longer and that's often because they're from rural locations and we will often keep our rural children, indigenous or non-indigenous, for a little bit longer as inpatients or ask them to stay close to the hospital for longer (1.07).*

Similarly, yet linked to wound healing, one participant said about discharge and Aboriginal and Torres Strait Islander children: *'…we have kept them until they're pretty much completely healed'* (6.03). One participant went so far as to say they will discharge patients if *'we have people [healthcare professionals] there [remote location] that have the skills, have the knowledge that can carry on that care'* (3.11).

For some participants (6.05, 1.01, 4.05), discharge decisions were based partly on the home environment to which a family was going. *'If we don't think we're going to discharge someone, it doesn't matter who or what they are, back to a safe environment and know that they're going to have follow-up care we'll keep them in'* (6.05). A safe environment was also considered by one participant (4.05) when making decisions about discharge, however Aboriginality was a compounding factor.

> *Talking about Aboriginal and Torres Strait Islander peoples. I always want to lean towards keeping kids in longer…so that we can keep an eye on them. We just don't know a lot of the time about what environment, it's so multi-factorial, but I think we just see a lot of the time that when they leave things tend to fall apart a little bit and then they take longer to heal and then obviously it sort of follows on to sort of worse scarring outcomes, whereas I suppose sometimes I feel that if we can keep them here, keep them really well nourished, keep their dressings clean and all the rest of it then we might sort of limit a lot of the long term complications, but that doesn't necessarily always happen because there's always a push for beds and strictly speaking, they don't need to be here (4.05)*

A similar example about an Aboriginal and Torres Strait Islander child was provided by a medical participant.

> *…we hang on to them a bit longer sometimes but not always. I remember one little boy who was devastated by being here…I made the decision he's got to go back to [the hospital close to his home]…so sometimes we do keep them longer because we know when they go back their risk of secondary infection is higher and so we'll hang on [to them]. A few days later when I saw him smiling on the television in the hospital with his grandmother, I said there we go, we learn from this (5.04).*

One participant described partly determining discharge on availability of family support. '*I've got to see what resources are there and I'm also talking to them about what sort of family they've got out there, who they live with, how many people live in the house'* (4.03). Another participant said they discharge based on family confidence and ability to provide the necessary care for the child (3.11). Discharge decisions were also based on a combination of family support and capacity for care, access to follow-up care and on wound healing stage (6.02, 4.02).

Sub-theme 2.3 – Delivery of care

2.3.1 Compliance with care

Many participants referred to patient 'compliance' when talking about difficulties with care regimes, especially as it relates to follow-up care and genuinely wanting the best for clients (1.07, 1.13, 2.07) as said by one participant. Most burns team members *'genuinely do care about the patient and want the best for them and sometimes it's very frustrating when you're thinking, I can see something bad is happening…[yet] you have to work within the constraints of appropriate care'* (2.07). One participant said that *'to assist their engagement and I guess, compliance, although I don't like that word compliance, you know, their engagement with the therapies that we're prescribing for them…'* (1.07) they will engage in better conversation. Another participant thought patient compliance might be improved through patient's seeing poor outcomes (2.07). This was mostly in relation to scarring. One participant talked specifically about compliance and Aboriginal and Torres Strait Islander children, saying:

> *…they're much more difficult to manage, some of them come from little communities and they haven't really seen white people, they're unco-operative, they certainly try to rip splints off, they won't eat and drink and I think if you get the parents involved in doing things you're more likely to be successful in the ward situation. I think there's a whole new issue when they go back home, that's a different thing. I think the compliance level drops to most of the time somewhere around zero, it doesn't matter what they say, they don't wear the garments, they don't wear the splints, they don't come to appointments, they don't do physio and the end result for a lot of them is bad and I don't know the answer to it because even if the local medical centre is trying to get them, they just don't come in (3.04).*

2.3.2 Relationships with children and families

Many burns team staff described spending time building good relationships with families. They do this with the hope it will make their work easier, and families more likely to engage with care regimes and the challenging requirements inherent with burns rehabilitation. One participant said it is *about 'getting a relationship that they will want to maintain…with us long term to then come back if we need them to…or perhaps a clinic that we can liaise with during that time'* (2.10). Participants reported becoming a friendly face in a foreign environment (1.09) who take *'…time, lots of time, lots of chat about things other than the injury'* (3.11) when building relationships. Taking time was described by a large number of participants as key to building good relationships with families. Participants also acknowledged the stressful environment of hospitals, exacerbated by having a child with a burns injury and the importance of having a relationship with *'…somebody in the system that they get on well with'* (1.12). Developing relationships with Aboriginal and Torres Strait Islander families was reported by two participants (3.11, 3.16) specifically and key to good burns care and outcomes. *'I'll work alongside [patient] to transition because again it's complex but also it just takes time to build that confidence with them as well, with that family'* (3.16).

2.3.3 Social work

There was general consensus in the data that social workers are:

> *…very important with burns injuries because the nature of burns injuries is that they tend to involve people from a low socio-economic background so they often have more problems before this injury happened and then you factor in the injury and then those problems become more significant and then it becomes really quite an issue for family to coordinate their care and management (2.07).*

Members of the burns team will recognise that a family needs social work if, for example, *'they're not coping financially or coming into the appointment okay, we'll flag for the social worker to pop in and chat to mum about that and maybe welfare can help them out'* (6.02). Most of the provision for social work was dedicated to inpatient care, however one site has a social worker providing care in their outpatient clinic (2.15). For this site also, a second social worker provides long term support. This was said to be because:

> *…there's a real recognition that new developmental stages raise new issues that are either new issues, or they're old issues that need to be re-worked because they're just cognitively more mature (2.16).*

Provision of social work support was reported similarly, especially amongst the social work participants. Two participants described using a psychosocial framework to assess families (2.15, 1.16). One of these participants said:

> *There's the psychological support, emotional support stuff which would be addressing specific issues, psycho-education is something that's pretty routine which is explaining and normalising emotional responses to trauma and ways that families can help their children through it and themselves. There will be crisis intervention which is when we feel that people really aren't coping, this would often happen earlier in an admission for some people and the people don't seem to be coping very well so we would put things into place to help them cope and that might mean maybe helping them with stuff at home, getting someone in to help them with other children…maybe some financial stuff to help them get in and out of the hospital and manage their other children, help brainstorm with them things that they can do to help them cope with the admission, that sort of thing (1.16).*

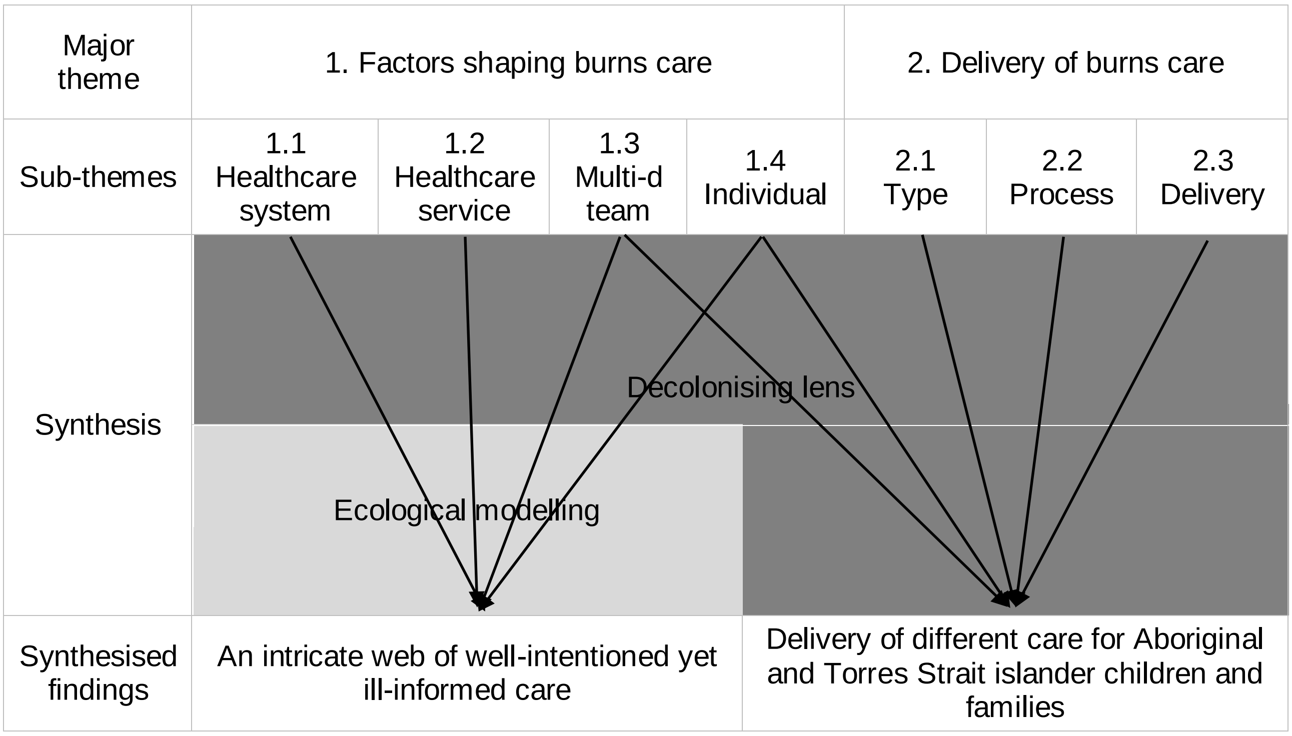
Inductive thematic analysis summary

I have described the broad findings following the inductive thematic analysis of the data. This includes an outline of the key components or aspects that shape burns care and a summary of participants' descriptions of the delivery of burns care. Many aspects of the data indicate a very interrelated system for burns care in Australia, and analysis identified connections between those things that inform care and the delivery of care. For example, a number of quality indicators guide clinical care, and some discharge decisions relate to the perceived compliance or non-compliance of families to care.

Synthesis of data

Further synthesis of data through the use of a theoretical decolonising lens resulted in the identification of two major concepts: 1. an intricate web of well-intentioned yet ill-informed care; and 2. the provision of different care for Aboriginal and Torres Strait Islander children and families. Figure 5 presents a diagrammatic representation of these synthesised findings. Chapter eight contains a manuscript under review with the journal *Burns* and has a focus on the data concerning what informs the care that burns teams provide, for Aboriginal and Torres Strait Islander children and families. In chapter nine I present a manuscript under review with the *International Journal for Equity in Health*, highlighting the findings from the synthesis of data regarding different burns care for Aboriginal and Torres Strait Islander children and families. A summary of each finding is presented below.

Figure 5 - Synthesis of findings



Major theme	1. Factors shaping burns care				2. Delivery of burns care		
Sub-themes	1.1 Healthcare system	1.2 Healthcare service	1.3 Multi-d team	1.4 Individual	2.1 Type	2.2 Process	2.3 Delivery
Synthesis	Decolonising lens						
	Ecological modelling						
Synthesised findings	An intricate web of well-intentioned yet ill-informed care				Delivery of different care for Aboriginal and Torres Strait islander children and families		

Synthesised Finding 1: Various factors inform burns care (chapter eight)

The further synthesis of data identified burns care in Australia is informed by an intricate web of compounding factors. Australia's dominant Western biomedical health paradigm governs overarching healthcare system policy and statewide approaches to burns care. Services are informed by evidence derived in a Western research paradigm, strive to meet quality indicators of a mostly clinical nature and apply good intentioned, yet ill-informed, measures across jurisdictions to meet the needs of Aboriginal and Torres Strait Islander children. Data showed individual clinical and administrative staff are conflicted by their desire to provide care they think is best for Aboriginal and Torres Strait Islander children, their individual implicit bias, and the direction given by those people and systems in power. These findings are reported on in manuscript form in chapter eight.

Synthesised Finding 2: Provision of different care for Aboriginal and Torres Strait Islander children and families (chapter nine)

The focus of analysis on a specific sub-set of data suggests that burns team members' approaches to care for Aboriginal and Torres Strait Islander children fell into three main categories. These include team members who: 1. understand the requirement to meet the specific needs of Aboriginal and Torres Strait Islander children and deliver different care; 2. believe in the provision of the same care, but deliver different care based on needs, and 3. those that see little need for the provision of different care for Aboriginal and Torres Strait Islander children and value the provision of the same care above all. Reasons why participants reported delivering different care included awareness of their own biases; having an awareness of the incongruences between the ways of Aboriginal and Torres Strait Islander families and that of the health system, and knowledge of identified risk factors. Furthermore, health professionals may conflate equitable and equal burns care, which has implications for the delivery of burns care for Aboriginal and Torres Strait Islander children and families. These findings are reported on in manuscript form in chapter nine.

Chapter summary

The analysis of this data identified many aspects of burns care relevant to Aboriginal and Torres Strait Islander children. During both the data analysis and the synthesis of data stages, important factors became apparent as they relate to the overall NHMRC project (Ivers, Hunter, Clapham et al. 2015). These factors require triangulation with other data for greater cross-interpretation and synthesis of the findings. Some of these factors will be explored in the discussion chapter.

CHAPTER 8 – What informs care? Descriptions by multidisciplinary teams about burns care for Aboriginal and Torres Strait Islander children

The work presented in this chapter is in manuscript form and has been submitted for publication in the international journal *Burns*. The manuscript was submitted in December 2018 and is currently under review. This manuscript presents the findings related to one of the two main concepts identified in the data analysis process (see chapter 7, Figure 5). This concept being presented in this chapter is regarding 'factors informing care'.

Citation
Fraser, S, Mackean, T, Grant, J, Hunter, Keeler, N, Teague, W, Clapham, K, Potokar T and Ivers, RQ 2019, *What informs care? Descriptions by multidisciplinary teams about burns care for Aboriginal and Torres Strait Islander children*, Burns.

Attribution of Authorship
Authors SF, JG, TM, KH and RI all contributed to the conception and design of this manuscript. Data collection was completed by SF, and analysis and interpretation of research data was performed by SF and NK, and contributed to by authors JG, TM, KH, and RI. Drafting of the manuscript was completed by SF, and revision of significant parts of the work so as to contribute to the interpretation was contributed to by SF, JG, TM, KH, NK, WT, KC, TP and RI.

Introduction

Burns injury in children can be devastating, causing life-long scarring, severe psychological trauma and loss of function in multiple domains (WHO 2008). In Australia, Aboriginal and Torres Strait Islander children experience burns injury at least double the rate of other children (AIHW 2011a). There is evidence that burns care is best delivered from a platform of multidisciplinary experts and specialist facilities (Al-Mousawi et al. 2009) and that high quality care is fundamental to good outcomes in burns care (Sheridan et al. 2000). Quality healthcare for Aboriginal and Torres Strait Islander children and families is known to be different to that for non-Indigenous children (Mackean 2009). Such differences include an '*appreciation of the healing strengths of reconnecting with family, culture and Country*' (Mackean 2009), cultural competency in health systems and healthcare (Bainbridge et al. 2015) and cultural safety (Best & Fredericks 2018). Differences in ways of health and healing exist as a result of alternate knowledge systems(Durie 2005) and are likely to mean burns care needs to be different for Aboriginal and Torres Strait Islander children than that administered to non-Indigenous children.

In Australia the normative approach to healthcare is based on scientific knowledge from a positivist paradigm in the form of a primarily biomedical model (Best & Fredericks 2018). In tertiary healthcare settings, healthcare specialities result in segregation of the human body (Scrimgeour & Scrimgeour 2008) with a focus on the physical or biological aspects of disease and illness, also known as a reductionist model (Best & Fredericks 2018). This is different to Indigenous models where peoples' ways of health and healing encompass a holistic view of health (Australian Indigenous Doctors' Association 2010). The consequences of these differences, or disjuncture of knowledges (Durie 2005) are evident in the disparities in healthcare experienced by Aboriginal and Torres Strait Islander peoples (Dwyer et al. 2011). They include barriers in access to tertiary and primary healthcare for Aboriginal and Torres Strait Islander people in both urban and rural/remote settings in Australia (Scrimgeour & Scrimgeour 2008). In urban areas, these barriers relate to the unacceptability and inappropriateness of how healthcare services address complex health and social conditions and cultural safety (Scrimgeour & Scrimgeour 2008). Similar disparities in access to healthcare and in health outcomes exist for Indigenous people worldwide (King, Smith & Gracey 2009).

In Australia, burns injury models of care have been developed to inform system-wide multidisciplinary teams in the delivery of specialist care. Significant shortcomings exist in these models of care in relation to their development and content concerning quality and cultural safety for Aboriginal and Torres Strait Islander children and families requiring burns care (Fraser, MacKean, Grant et al. 2017). It is also not clear if or how these models are used to inform care, or what other factors, including those synonymous with cultural competency, inform the delivery of burns care in Australia. Furthermore, little is known about how multidisciplinary teams functioning in large tertiary settings provide burns care that meets the needs of Aboriginal and Torres Strait Islander children and families. Despite the significant burden of burns injury in Aboriginal and Torres Strait Islander children (AIHW 2011a), continued high incidence of hospitalisation (Möller, Falster, Ivers et al. 2016), recognised healthcare access disparities (Scrimgeour & Scrimgeour 2008) and a disjuncture of knowledges (Durie 2005), no work examines how burns care is delivered in Australia for this population (Ivers et al. 2015) from the perspective of the service providers. As a result, it is unclear how the disjuncture of knowledges manifests in burns care for Aboriginal and Torres Strait Islander children and families.

To address this we explored what informs burns care across Australia in and from large tertiary settings from the perspective of those involved in the delivery of burns care to Aboriginal and Torres Strait Islander children and families. This investigation will contribute to the development of burns injury models of care that facilitate more appropriate and accessible burns care for Aboriginal and Torres Strait Islander children and families. Our insights into burns care in the Australian context for Aboriginal and Torres Strait Islander children and families may also be applicable to other surgical conditions or international Indigenous settings.

Methods

Methodology

Interface research methodology from a decolonising perspective was engaged to explicitly explore the disjuncture of knowledges as it relates to burns care. In terms of healthcare, to be decolonising means to challenge existing and normative ways of thinking about biomedical models, and to consider Indigenous concepts of health and healing (Smith 2012). This was achieved using Durie's (2005) principles of research at the interface of knowledges and the principles of cultural safety (Best & Fredericks 2018). Interface research methodology provides an opportunity for integration and interfacing of Aboriginal and Torres Strait Islanders peoples' knowledge and scientific concepts (Durie 2005), and can be likened to Ganma (Pyrch & Castillo 2001). Ganma describes when fresh and salt water meet and a new environment is created (Pyrch & Castillo 2001). Ganma can be a metaphor for the coming together of different knowledges, for the creation of new knowledge. This methodology provided opportunities to rebalance the use and application of different knowledges and make new understandings relative to the specifics about burns care for Aboriginal and Torres Strait Islander children and families.

Study design

Following an interface research approach (Durie 2004, Durie 2005) principles of mutual respect, shared benefits, human dignity and discovery guided the research process. This approach was implemented through a qualitative study design (Patton 2015) by interviewing clinical and administrative burns team staff to investigate self-reported descriptions of what informs the burns care they deliver in Australia for Aboriginal and Torres Strait Islander children and families. Participants across six tertiary hospitals in Australian were recruited using purposive sampling (Patton 2015) following ethics approval in each jurisdiction, including site specific governance approvals. Lead burns clinicians at each site were contacted about the study for a list of burns team staff and corresponding email addresses. Arrangements were made for on-site visits. Clinical and administrative burns team staff were invited to participate via email prior to the researcher's visit. Professional information about the researcher (author SF) and key study details were provided. Potential participants responded to the researcher individually to make arrangements for an on-site interview. Staff were also invited to participate in the study during the researcher's visit. Data were collected individually and at mutually agreeable times in private office spaces. Face-to-face interviews were conducted using a semi-structured interview guide and were audio recorded.

Field notes were also taken during and after the interviews. Interviewing at each site was ceased when no new data were being collected and saturation was reached.

Analysis

Interviews were transcribed verbatim, checked for accuracy by the participant, and then de-identified. No interviews were repeated. Transcripts were imported into NVivo 11 qualitative analysis software (QSR International). An inductive content thematic method (Patton 2015) was used to analyse data. This was overlaid with a decolonising lens to facilitate consideration of theoretical constructs informing burns care for Aboriginal and Torres Strait Islander children and families (Smith 2012).To translate and apply initial content and theoretical findings for use in health service delivery, an ecological framework (Reilly et al. 2011) informed further examination of the data. Where Indigenous knowledge is situated as dynamic and relational (Durie 2005) the ecological framework enabled data to be considered and presented in context and across different levels of the healthcare system from national policy to the individual level. This enabled identification of those things that inform burns care as the outcome of interactions among many factors across multiple levels. Applying Ganma (Pyrch & Castillo 2001) in research processes facilitated multiple theories to come together at the interface for analysis.

An ecological framework also provided a space to actualise the significant influence of policy on healthcare. This is important given the negative consequences to health outcomes that past and current Australian policy has on Aboriginal and Torres Strait Islander peoples (Couzos & Murray 2008). The ecological framework also enabled a more holistic approach, well aligned to those connections Aboriginal and Torres Strait Islander peoples have to community, Country and culture that are interdependent and broader than oneself (Durie 2005).

In line with interface research methodology, methods to ensure Indigenous knowledge consideration and inclusion were engaged. As such, contribution to data analysis was sought from Author NK, an Aboriginal woman external to the main project, yet linked to the main researcher through a cultural mentorship role. With extensive experience in healthcare programs and qualitative research, NK was invited to analyse six purposely selected transcripts in their entirety and sections of an additional six transcripts. The selected transcripts included participants from a mix of jurisdictions, with varying levels of seniority and engaged in different professions. The additional sections of transcripts were selected because of their challenging content. Follow-up discussions between the main and invited data analyser facilitated consideration of differing coding and reflective insights. Regular discussions with the investigative team including with author TM (a PHMO of Waljen descent), and Aboriginal and non-Indigenous investigators on the larger study also informed and validated the data analysis process throughout the project. Consistent with the coming together of Indigenous and Western knowledge, these processes contribute to the reliability of data analysis and demonstrate our application of interface research methodology.

Results

Over a six month period in late 2016 to early 2017, 76 (n=57 female) interviews from an approximate total of 120 clinical and administrative staff across six sites (Table 9 - Participant summary) were conducted. Duration of interviews were between 30 and 80 minutes. Those who did not participate did so due to unavailability. Of the 76 participants, 57 reported having attended cultural awareness training, with eight Aboriginal and Torres Strait Islander participants not attending, and the remaining were either not asked (n= 6) or stated they had not attended (n=5).

Table 9 - Participant summary

	Nursing	Aboriginal health practitioner	Medical	Allied health	Aboriginal / Indigenous liaison officer	Administrative
Site 1	4	-	3	6	3	-
Site 2	5	-	4	6	-	1
Site 3	4	-	4	6	1	1
Site 4	2	1	2	4	1	-
Site 5	2	-	2	4	1	1
Site 6	3	-	1	2	1	1

The results are presented in two sections. To begin with, an overview of the analysis is presented. This is followed by a four-part detailed account of the themes identified to inform burns care. Direct participant quotes have been used throughout to illustrate themes. The term clinician is used as a collective for all clinical participants; with medical, nursing and allied health titles used where necessary to develop understandings. Position titles are used for all other participants.

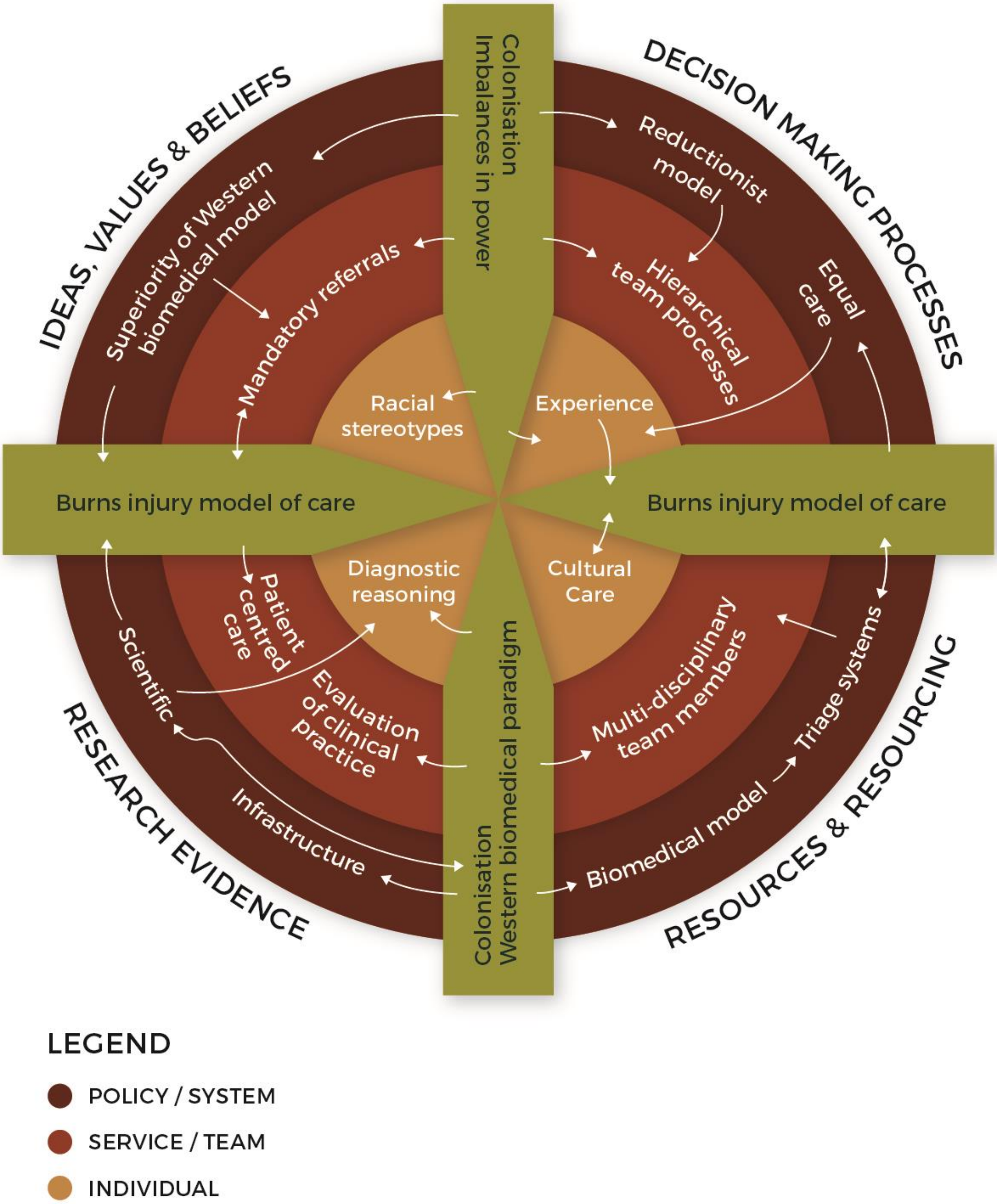
Overview

Content analysis indicated that evidence, resources and resourcing, decision-making processes and values and beliefs informed the provision of burns care for Aboriginal and Torres Strait Islander children and families in Australia. Colonisation and imbalances in power relations were identified as informing burns care through an overlay of decolonising theory. Ecological modelling (Reilly et al. 2011) indicated that all themes are situated in a layered construct across the healthcare system (Figure 6).

The nature of evidence informing burns care was found to be fundamentally grounded in a biomedical health paradigm, including through profession-specific frameworks and particular approaches to care. Data highlighted that strategies to provide best care for Aboriginal and Torres

Strait Islander children and families are limited by current resourcing. Telehealth was an exception that was well-resourced. The importance of medical experience in decision-making processes was apparent in informing burns care, at the same time as facilitating imbalances in power within a hierarchal system. Burns team members' assumptions about how Indigenous status is identified, values placed on the idea of equal care and stereotyping beliefs also informed burns care. Participant beliefs regarding individual and system responses to the provision of equitable burns care for Aboriginal and Torres Strait Islander children and families were major themes identified across the data set. Detailed analysis and reporting of these data relating specifically to the provision of equitable care is beyond the scope of this report and will be available in a later publication.

Figure 6 - Ecological modelling of results



Themes

The nature of evidence

It was evident from the data that scientific research evidence informs the physical aspects of burns care at a national level which infiltrates and influences healthcare at the service, team and individual levels. Australia's health system supports burns care to be delivered in and from (eg telehealth) large tertiary settings and focuses mostly on biological aspects of health. This is evidenced by the way clinicians spoke predominantly about assessment of wound size and depth, triage of children based on burn severity and surgical intervention. Evaluation of clinical practice at the health service level provides the evidence to inform practice and units are required to meet quality indicators predominantly focused on surgical intervention. A medical participant said:

> *...we also look at the difference between the day of decision to graft and the graft as a measure of our efficiency of our theatre so that's a KPI and there are other KPIs about time to heal and so on. So we do look at that data on a monthly basis.*

Another medical participant explained evaluation of evidence derived by burns units are then directly applied in practice:

> *…as soon as the results are in, if it shows a significant benefit whichever intervention you're looking at then we put it into place straight away so it becomes part of the way we do things. It just becomes clinical practice and translated into clinical practice immediately.*

However, very few participants reported using research evidence to inform their psychosocial or cultural care.

Data indicated that models of care document burns care pathways in order to inform triage processes and referral pathways into tertiary settings. One medical participant reported that models of care were sometimes developed retrospectively to articulate the way burns units deliver services.

> *The model of care wasn't written to direct the way we work, the model of care was written to articulate the way we work. We haven't written a model of care and said work to that, we've written down what we do, and it has become our model of care.*

Profession-specific frameworks like theoretical social-work frameworks also inform care; as do guidelines related to different professions that sit outside of an exclusive model of care for burns injury. Clinicians also described being informed by notions of patient-centred and family-centred models of care as described by one nurse as: *'…using the model of family centred care that is very big in burns because the family are here'*.

Resources and resourcing

Allocation of financial resources informs burns care and access to services and can encourage or restrain culturally competent burns care for Aboriginal and Torres Strait Islander children and families. At the health system level, triage via well-resourced and highly functioning telehealth systems in three of the six jurisdictions informed burns care for children and families who are geographically disperse, described by one medical participant as: *'…a very rigorous triage system. In six months the videoconferencing program saved $1.7 million in flights'*.

A small number of participants felt inadequate in delivering culturally safe burns care services, however not all participants reflected on their ability to do so. This was coupled with evidence of inadequate cultural awareness training at individual levels and the need for further development of cultural competence by health services. An Aboriginal health practitioner commented:

> *Our cultural awareness training really lets staff down because it only addresses the first part of the cultural continuum of going towards…delivering a culturally safe service. So we only get the awareness part and I feel sorry for the staff because the staff really want to do the right thing but because there's no resources around [it is hard].*

Whilst Aboriginal/Indigenous liaison officers A/ILOs were employed in all health services, existing barriers interfered with access and this impacted on the ability of children and families to be seen. Nursing staff felt pressured to complete clinical tasks and reported not having enough time to prioritise spending it with families. Participants across a range of professions also described the limited resources available to support cultural care of children and families. As a result, they could not provide everything they would like to or saw as necessary, or have the required resources to meet the needs of Aboriginal and Torres Strait Islander children and families. This was described by an allied health participant:

> *We don't have like culturally appropriate handouts and a lot of it is narrative and story-telling with them, which works really well but it would be nice to also have some other stuff to share. We don't have the time or the resources to do anything about it at the moment but that's a goal.*

And further explained by an Aboriginal health practitioner:

> *If a person wants to get spiritual needs addressed they need to abscond…they come back, if it's a cleaning ceremony, usually that's the head shaved…and they come back to the hospital and then most people think uh oh psychotic episode, especially if there's a language barrier. There's not enough catering for that side of health'.*

Limited or inadequate clinical care resources and resourcing informed care practices. This included such things as not employing enough nursing staff and differing access to allied health staff in non-metropolitan areas.

There were differences between healthcare services in terms of the types of professions engaged within the multidisciplinary burns team. One unit employed a play therapist for procedural distraction and an anaesthetist in their burns outpatient clinic. Another facility employed an Aboriginal health practitioner who had a clinical role, part of which was with children requiring burns care. For some services, physiotherapists contributed extensively to care, but for others it was mostly occupational therapists. In one service, a nurse practitioner was employed to facilitate outpatient care. It is not clear if services' models of care dictated resourcing (or not) of certain professions to meet the perceived requirements; or if allocated resourcing resulted in engagement of the various professions and subsequently the delivery of care.

Decision-making processes

At a health service level, data indicated that burns care teams were supported to establish a hierarchical structure, where decision-making and care is most often led by medical staff. Services support the development of these structures through existing policy frameworks and through the systems at large being built within a Western biomedical paradigm. As described by one medical participant as: '…*ultimately because of the way our infrastructure is then the surgeon is the team leader, that may change in the fullness of time but right here, right now that's it*'. Stated by one medical participant as: '…*everyone deserves consultant led care'*.

Conversely, data from across the sites did refer to nurse-led outpatient clinics, whereby one medical participant said:

> *I will support a decision that may not be the one I've made but I recognise that it's made for the good reasons around and if [senior burns nurse] made that decision and I will support that decision in my role and facilitate that because I think it's really important, you can't put people in positions with decision-making and then pull the rug from underneath them.*

This participant went on to say: '*…I think collaborative decision-making is possible and do-able and that's what we do on a daily basis*'.

Individual experience was found to guide care whereby participants described seeking guidance from other clinical experts, often medical staff, with less experienced staff seeking guidance from senior clinicians within their profession. The experience was often based on longevity in a role rather than currency in expertise in the provision of burns care for Aboriginal and Torres Strait Islander children and pronounced by one allied health participant as: '…*we tend to work to the beat of [experienced clinician's] drum which is largely not documented*'.

Burns care was informed through clinicians in the multidisciplinary team seeking the expertise of others perceived as being better skilled to increase families' understanding of burns care; often about informed consent. This was evident in the data through the reporting by nurses of the use of available and specialised resources to enhance understanding, however not through the use of interpreting services. An Aboriginal health practitioner reported that they: *'[…give support with] easy things, or things that we think are easy like communicating with staff so [families] are able to give true consent'*. In regards to obtaining informed consent, a medical participant stated nurses have often: *'…actually come back and sat down with them for a longer period of time and talked about things'*.

The care pathways in documented models of care were said to be used to orientate new staff and educate services outside of the tertiary service on care pathways. The majority of participants also reported a multidisciplinary approach as informing their model of burns care. This was described as being mostly through attendance at standardised team meetings and case conferences. How input from different members was used to inform care at these multi-disciplinary meetings was not clear in the data. Models of care also recorded referral pathways (mandatory, and not).

The A/ILOs were often not included in regular burns team meetings. This shows a lack of support at the service level to ensure all knowledges and skills relevant to culturally competent burns care are included in the multi-disciplinary team. This also demonstrates that physical-based health models continue to be privileged in burns care for Aboriginal and Torres Strait Islander children and families. While some clinicians did report seeking the support of an A/ILO in the care of Aboriginal and Torres Strait Islander children with a burns injury, this was not consistent or considered mandatory. One medical participant anecdotally reported: '*I felt that the patients are often referred but…they're not seen and it's not because people haven't tried'*.

Ideas, values and beliefs

Data indicated that identification of Indigenous identity by clinicians was based mostly on appearance of skin colour and sometimes on surname. An example of this was described by one allied health participant: '*I don't always know whether somebody is an Islander or Aboriginal because a large percentage of our families are olive skinned and sometimes I'm not sure what nationality they are'*.

This was confusing as data indicated these tertiary healthcare services have practices in place to systematically identify Aboriginal and Torres Strait Islander people. When asked, clinicians reported that children and families are asked if they identify as Aboriginal and Torres Strait Islander on admission to the facility. As a result, clinicians did not further seek out Indigenous identity from children and families. Despite having this information, they reported not checking patient records for Indigenous identity and used skin colour as the main indicator.

When asked about the need or provision of different care for Aboriginal and Torres Strait Islander children and families, an overwhelming number of participants stated care is the same for everyone; highlighting participants' value of equal care. One nurse stated: '*I don't treat any of my patients differently so whether you're Aboriginal, African, Muslim, whatever, you're one of the same for me'*.

In contrast, many clinicians also believed that Aboriginal and Torres Strait Islander children should stay in the tertiary settings until wounds were completely healed rather than return to their families, unlike non-Indigenous children. The fear of losing a surgical graft motivated one medical participant's beliefs regarding discharge:

> *The most important risk of losing a graft is, one is mobility, secondly infection. That grafted area we don't want it to be mobile, we don't like any shearing force on that otherwise the graft moves and wouldn't take up, the whole exercise is defeated in that case. So for that*

> *reason, for some reason Indigenous families, we have a fear that they may not adhere to the principles so for that reason at least if we keep them in the hospital so they'll stay quiet and that way we give enough time for the burn to heal. So that's the most important reason and secondly there is a risk of infection, everyone has got a risk of infection, recognition of that infection is important. Again the fear is if Indigenous families, if they go home the fear is whether they will be able to recognise an infection early or not. If they don't recognise infection and if they sit on it the graft will be lost, not only that the infection can get into a system and sepsis and all those issues. So I think these are the main factors…to keep them in the hospital.*

In the above quote it is clear that deficit beliefs about Indigeneity inform care, however it was sometimes difficult to ascertain from the data whether beliefs regarding discharge were based on skin colour, Indigenous identity, or deficit beliefs demonstrated by fears or pragmatisms about remoteness. Nonetheless, clinician beliefs about identity and skin colour and ability (or lack thereof) to care for a burns wound were evident in the data and informed care outcomes.

Data reported from participants highlighted that the value placed on various professions within a multidisciplinary team's model of burns care differs. For example, the referral to, or inclusion of, an A/ILO in most services was not mandatory. However, for most of the services, referral to the social worker was mandatory and linked to a key performance indicator of quality. This may reflect, or at least be contributed to, by the reported lack of A/ILO availability in the tertiary healthcare setting.

Discussion

Overview

Tertiary healthcare services typically provide the complex medical and surgical procedures essential for the physical and biological components of burns care (Sheridan et al. 2000). For some populations such as Aboriginal and Torres Strait Islander peoples, health is a broader construct than physical or biological, and medical or surgical care alone is not enough to meet all health needs (Australian Indigenous Doctors' Association 2010). The factors identified by participants as informing their care of Aboriginal and Torres Strait Islander children with burns are now discussed in relation to concepts that contribute to good health and healing for Aboriginal and Torres Strait Islander children and families. The principles of cultural safety (Best & Fredericks 2017); reflexivity, regardful care, dialogue, power imbalances and decolonisation provide a framework to facilitate articulation of these constructs. Recommendations for transformational and sustainable change including strategies for implementation into practice as the result of the interfacing of knowledges are offered throughout.

Reflexivity

Some of the ideas, values and beliefs evident in the data of this study reflected constructs aligned with colonisation, including racism, that continue to inform burns care for Aboriginal and Torres Strait Islander children and families in Australia. Expressing stereotypes, prejudice or discrimination is a form of racism (Paradies 2016). While participants described valuing good health outcomes for Aboriginal and Torres Strait Islander children, like absence of wound infection or a skin graft 'taking'; decisions were based on a deficit belief. This is evidenced by participants' belief that risks of infection are higher outside of the tertiary healthcare setting. Geographical remoteness may have also contributed to some participants reporting of discharge decisions. However, believing that Aboriginal and Torres Strait Islander families are not able to care for wounds is grounded in deficit thinking and contributes to poor health (Larson, Gillies, Howard et al. 2007). Facilitated case study reviews that incorporate Indigenous knowledge would support more reflexive and culturally appropriate decisions and decision making processes.

Data in this study demonstrates a lack of explicit references to standards within relevant professional codes of conduct that might inform or enshrine culture competency and safety within the healthcare setting. There were no examples of burns care informed by a code of conduct acknowledging cultural safety or acknowledging the impact of colonisation in health outcomes of Aboriginal and Torres Strait Islander peoples. Released in April 2018, the nursing code of conduct (NMBA 2018) explicitly describes cultural safety and an acknowledgement of colonisation in the contemporary health outcomes of Aboriginal and Torres Strait Islander peoples. This code may help inform more culturally safe nursing practice in the future whereby a nurse must *'… reflect on the ways that your own culture and assumptions might impact on the care you give*' (NMBA 2018). Incorporating this approach for all health professionals, including allocation of time for reflexivity written into practice models and stipulating required parties with inclusion of Indigenous and non-Indigenous knowledges may improve capacity for reflexive practice.

This study suggests that burns team estimates of the number of Aboriginal and Torres Strait Islander children receiving burns care are underestimates due to reports that staff ascribe Indigenous status according to skin colour. This is a result of participant's values linked to racial stereotyping as evidenced through thinking that to be an Aboriginal and Torres Strait Islander person, one must have dark skin. As a result, burns care could be provided to more Aboriginal and Torres Strait Islander children and families than assumed. This observation is supported by a report (AIHW 2010b) showing 11% of Indigenous people were not identified correctly in their hospitalisation records where Indigenous status was self-reported. Reflexivity could be supported through the collection of data relevant to Aboriginal and Torres Strait Islander children and families and not only those related to identification. For example cultural affiliation and kinship relationships.

Regardful care

Data showed burns care for Aboriginal and Torres Strait Islander children and families is informed by medical and surgical expertise and intervention with support from nursing and allied health discipline frameworks, like those applied in social work. A/ILOs, a role established to address issues around inequitable access to tertiary healthcare (Victorian Government 2008) and Aboriginal health practitioners (AHP) are important contributors in care for Aboriginal and Torres Strait Islander children and families (Peiris, Brown, Howard et al. 2012). Data in this study indicated A/ILOs, AHPs and social workers address needs not primarily based in a biomedical paradigm. This is important when considering strategies for mitigating the disjuncture of knowledges through regardful care for better health outcomes for Aboriginal and Torres Strait Islander children with a burns injury. These professions represented six percent of those interviewed in this study.

Some data from this study indicated a recognition of the necessity of engaging these additional support services, namely the A/ILOs, in contributing to meeting the needs of Aboriginal and Torres Strait Islander children and families. This insight was met with the reality that health service resources are mostly focused on supporting the medical components of healthcare and that holistic care, including the resourcing of A/ILO positions, is under-resourced. In addition, and while best practice burns care is said to be from a multi-disciplinary platform (Al-Mousawi, Mecott-Rivera, Jeschke et al. 2009), data in this study also highlighted that the hierarchal team and care structures appear to inhibit the complete uptake of multidisciplinary input and in doing so, perpetuates the dominant healthcare model and the provision of care that is regardless of culture. The need for more A/ILO positions to address availability issues was made clear in the data, aligning with existing evidence (Ware 2013). This is linked closely to the reported low levels of Aboriginal and Torres Strait Islander peoples employed in Australia’s health workforce and corresponding improvement strategies (Australian Health Ministers’ Advisory Council 2016b).

Dialogue

Allocation of resources by current healthcare systems and explicit guidance in models of care which reflect consideration of both Indigenous and scientific health and healing concepts, will better inform culturally competent burns care. Elements of family-centred models contribute to good health and exemplify cultural safety and may prove beneficial in informing burns care for Aboriginal and Torres Strait Islander children and families. There is a need for burns units to ensure access to A/ILOs who are trained to/or are facilitated to be trained in burns care and in discharge processes. There is also a need for health services to have defined partnerships with community health services, and within and between individual doctors, that enable better discharge processes. Considering dialogue in a model of care by documenting partnerships with other stakeholders in care and the inclusion of Indigenous support staff to enhance communication with families is required. This would be in keeping with the Australian Safety and Quality Framework for Health Care (ACSQHC 2010a) and a way for the continuity of care to be held intact by these relationships.

Power imbalances

Data in this study suggests burns care in Australia is characterised by an uncritical perpetuation of colonising approaches to care. Colonisation is characterised by dominance in power relations, and subsequent oppression of Indigenous ways of knowing, being and doing (Smith 2012). Oppression of Aboriginal and Torres Straits Islander peoples' ways of knowing was evident through no mention of traditional healing, aside from one Aboriginal health practitioner stating cultural care was not well resourced. Oppression of ways of being was evident in the data whereby Aboriginal identities were based on stereotyping; and oppression of ways of doing was evident in the clinicians' belief of the need to keep Aboriginal and Torres Straits Islander children in tertiary health settings and not believing that Aboriginal and Torres Straits Islander families can look after wounds. The minimisation of power imbalances may be supported by clinicians addressing how the delivery of multidisciplinary patient-centred care translates to discharge planning and decisions around discharge. This may be addressed through inclusion of explicit guidance in policy, systematic inclusion of Aboriginal health practitioners in multidisciplinary burns teams and contribution to care.

Results of this study also highlighted a need for increased cultural competency to address issues of colonisation and imbalances of power for non-Indigenous burns team members and health services. Cultural awareness training is insufficient or only partly supports non-Indigenous health professionals with cultural competence development. Provision of culturally competent care is not sufficiently resourced nor prioritised at the health service level. Supporting clinicians in their cultural competence journey will help minimise power imbalances at the individual healthcare level.

Decolonisation

Scientific evidence that informs a reductionist health model is a privileged and dominant form of Western biomedical knowledge. The privileging of a positivist paradigm is evidenced at all levels from individual clinician through to policy (Figure 1). The other factors informing burns care related not only to one level, but also related to the jurisdictional environment in which participants were employed. Taking 'research evidence' as an example, it informs: infrastructure at the jurisdictional level; workforce at the health service level; the model of care informing practice across all levels; the team in terms of who is included in the multi-disciplinary team; and at the individual clinician level to inform diagnostic reasoning. This observation shows how individual clinicians are intrinsically linked to the team, unit, service, and system levels, yet there are times when productive interaction breaks down. For example, there were numerous challenges involving A/ILOs at the burns team level. This is because the A/ILO is not attached to a burns unit; rather they are attached to an entire service and the service is responsible for the resourcing of the A/ILO. This limits how they were able to participate at the team level. As a result, the overarching context created by national and jurisdictional policy and funding impacts all layers of burns care.

Seamless translation of research outcomes from on-site investigation of burns care into clinical practice is a common and accepted way of viewing and using biomedical evidence. As a result, only this form of evidence is considered for inclusion in burns care. This is the case for other care foci in Australia (Artuso, Cargo, Brown et al. 2013) and highlights uncritical use of evidence. This also shows a lack of consideration of the use of additional evidence that may be more applicable and better placed to support burns care and meet the needs of Aboriginal and Torres Strait Islander children and families. Decolonisation can be addressed here through the incorporation of cultural evidence, including social and emotional evidence, in the care of Aboriginal and Torres Strait Islander children and families.

Nuances in these data indicate a disjuncture of knowledges through the superior placement, recognition and dominance of Western biomedical health knowledge. Data from this study showed Australia’s health system predominantly resources scientific approaches to burns care; for example telehealth. Data showed support for the use of telehealth based primarily on economical arguments. For a small number of clinicians, use of telehealth was based on keeping children and families closer to their homes. While telehealth for paediatric burns care might have proven economic benefits (McWilliams, Gilroy & Wood 2007), it is not clear if or how telehealth meets the needs of Indigenous peoples (Fraser et al. 2017). For telehealth to be a decolonising modality for healthcare, practice needs to be regardful of and incorporate cultural competencies to ensure that the rights of Aboriginal and Torres Strait Islander peoples are fully realised.

To reduce health inequities, healthcare needs to be decolonising. This means that the system for burns care would include an overarching health paradigm and policy with corresponding funding that was augmented by the operationalisation of Aboriginal and Torres Strait Islander definitions of health and healing. The burns care health service would engage across its jurisdiction and its facility with the community that it services, including community organisations. Data in this study showed burns teams mostly did not include A/ILOs in care planning, and the health system in general did not recognise Aboriginal and Torres Strait Islander peoples’ ways of knowing, being and doing. A decolonising approach to burns care would include individual clinicians, working alongside A/ILOs in the multidisciplinary team. Furthermore, burns teams would be supported to work better with Aboriginal and Torres Strait Islander peoples, and teams would be fully cognisant of Aboriginal concepts of health, healing and engagement with community through funded workforce capacity development. Importantly, health services would resource burns teams to engage in reflective practice to help ensure and drive continuous quality improvement in burns care provided to Aboriginal and Torres Strait Islander children and families.

Strengths and limitations

This is the first study to investigate what informs burns care for Aboriginal and Torres Strait Islander children and families from the perspectives of burns care teams in Australia. Data identified that paediatric burns care in Australia is informed by a complex network of compounding factors. These factors inform burns care across different levels of healthcare including at a national and jurisdictional level, health service and burns unit level, and across teams and individuals. The ecological framework provided a systematic way of exploring how factors informing burns care for Aboriginal and Torres Strait Islander children and families interact across multiple levels across the healthcare system, relate to and influence each other.

Not all of the people employed and working within burns teams were interviewed, however the collection of a large amount of qualitative data from on-site face-to-face interviews with many burns team members enabled everyday practices to be comprehensively explored. Drawing on recruitment across multidisciplinary burns care teams increased the likelihood that all professions involved in the care of Aboriginal and Torres Strait Islander children and families were represented. As data collected was from burns team members only and did not include the viewpoints of families receiving care, the ability to understand how children and families feel about the burns care they receive was a limitation of the study.

Data collection with clinicians was enhanced by the principle researcher being a registered nurse (female PhD candidate) with a thorough understanding of health systems and processes. As the research was about health and healing for Aboriginal and Torres Strait Islander children, the process was potentially flawed because the principle researcher was a non-Indigenous healthcare professional primarily educated within a medical standpoint. This limitation was purposely addressed through Aboriginal oversight and involvement in research process and data analysis.

Conclusion

We found an intricate web of constructs that inform health systems and services and healthcare professionals in providing burns care to Aboriginal and Torres Strait Islander children and families. The use of an ecological framework provided a cohesive way to show how overarching healthcare context, created at national and jurisdictional levels, informs care at the health service and burns unit level, and also how those parameters and ideas influence care at a team and individual level. This analysis facilitated an ability to situate healthcare delivery at the individual level in the broader health system context. The values and beliefs embedded in the broader health system, of which the health service team and individual are located in, are heavily influenced by positivist paradigm. There was a need to understand this interrelatedness across all levels of the Australian healthcare system and across the various factors informing burns care as it relates to Aboriginal and Torres Strait Islander children and families. This is important as factors informing care are not separate from each other; rather they are interdependent on one another. As a result, there are clear opportunities to improve healthcare for Aboriginal and Torres Strait Islander children and families in Australia; especially as it relates to burns care. Burns care, currently informed by a biomedical paradigm, with colonial ideologies informing service structure and clinician beliefs, can be improved by the careful consideration, inclusion and uptake of evidence linked to better care for Aboriginal and Torres Strait Islander children and families.

The difference between a clinician's intentions and resultant care for Aboriginal and Torres Strait Islander children and families may be due to a lack of adequate resourcing as well as a lack of Aboriginal and Torres Strait Islander knowledge input. While many clinicians want to provide better and more appropriate burns care for Aboriginal and Torres Strait Islander children and families, there is tension between the competing demands for achieving clinical quality indicators, organisational efficiencies and decolonising a system entrenched in colonial ideologies.

Burns care for Aboriginal and Torres Strait Islander children and families in Australia is still predominantly informed by non-Indigenous concepts of health, healing and care delivery. The disjuncture between Western biomedical and Indigenous healthcare paradigms negatively impacts the delivery of care to Aboriginal and Torres Strait Islander children and families. Burns is an important but not isolated example. The current power imbalance in favour of the scientific approaches to burns care extenuates this negativity, and constructive action is required to address this inequity.

Chapter summary

In this chapter I presented findings from multidisciplinary burns team data on what informs burns care in Australia. A web of complex factors including evidence, resources and resourcing, individual clinician decision making processes and beliefs, and models of care were found to inform care. As a result, there is a need for changes in the way evidence informs policy and practice in burns care for Aboriginal and Torres Strait Islander children and families so that it incorporates Indigenous constructs of health and wellbeing.

CHAPTER 9 – Considering difference: clinician reports of providing equal and equitable care for Aboriginal and Torres Strait Islander children and families

The work presented in this chapter is in manuscript form and has been submitted for publication in *International Journal for Equity in Health.* The manuscript was submitted in February 2019 and is currently under review. This manuscript presents the findings related to one of two main concepts identified in the data analysis process (see chapter seven, Figure 5) and arising from a subset of the data. This concept being presented in this chapter is regarding the ‘provision of different care’.

Citation
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Background

A just and healthy society is reliant on the equitable distribution of health outcomes (Marmot et al. 2008). While different definitions exist, Whitehead (1991) defines: equity as the absence of avoidable differences among groups of people; equality as the state of being equal, especially as it relates to rights and opportunities; and inequities as unfair differences. Health inequities are disparities in health that are unnecessary, avoidable, unfair and unjust (Whitehead 1991). Health inequities arise from the social and material circumstances in which people grow, live, work and age (Marmot et al 2008), and through cultural exclusion (Global Health Europe 2009). In Australia, Aboriginal and Torres Strait Islander children experience health inequities across many domains (Rothstein, Heazlewood & Fraser 2007), including the experience of burns injury at disproportionally higher rates than non-Indigenous children (Möller et al. 2017). This has been a longstanding inequity (Duke, Wood, Semmens et al. 2011, Riedlinger, Jennings, Edgar et al. 2015). Furthermore, disparities exist in quality indicators for Aboriginal and Torres Strait Islander children and non-Indigenous children following a burns injury (Moller et al. 2017).

Good quality and specialist multidisciplinary burns care is required for the best health outcomes following a burns injury (Al-Mousawi et al. 2009). For Aboriginal and Torres Strait Islander children, this includes the provision of healthcare that is culturally competent and relative to their context (Bainbridge et al. 2015). Equitable care that addresses the specific health needs of Aboriginal and Torres Strait Islander children and families, and care that is experienced as culturally safe, is required (Laverty, McDermott & Calma 2017). There are gaps concerning the quality and cultural safety of the models that inform burns care (Fraser, Grant, Mackean et al. 2018), and little is known as to how multidisciplinary burns teams consider equitable healthcare for Aboriginal and Torres Strait Islander children (Ivers et al. 2015). This paper explores the constructs of equity and equality in the context of burns care as part of a broader study investigating burns care for Aboriginal and Torres Strait Islander children.

Methodology and methods

A disjuncture exists between the ways of knowing, being and doing of Indigenous and non-Indigenous people (Smith 2013). This is the case in Australia. Interface research methodology (Durie 2005) informed an exploration of the disjuncture of knowledges related to burns care for Aboriginal and Torres Strait Islander children and families in Australia. Interface methodology provides an opportunity for integration and interfacing of Aboriginal and Torres Strait Islanders peoples' knowledge and Western concepts(Patton 2014). This approach was integrated with a qualitative study design (ACSQHC 2010) to investigate burns care for Aboriginal and Torres Strait Islander children and families.

Multi-centred ethics approvals were obtained (Table 6) and clinical and administrative staff employed in paediatric burns teams across six tertiary hospitals in Australia were recruited using purposive sampling (Patton 2014). Data were collected from late 2016 to early 2017 in audio-recorded face-to-face interviews using a semi-structured interview guide (Appendix 12). A sample of *n*=76 burns team members reported on burns care. Almost all participants (*n*=65) were specifically asked if they provide different care for Aboriginal and Torres Strait Islander children compared to non-Indigenous children. The eleven participants not asked about this matter were either Aboriginal/Indigenous Liaison Officers (A/ILO), Aboriginal health practitioners (AHP), or not asked due to time limitations. Interviews were transcribed verbatim, checked for accuracy by the participant, and then de-identified. Transcripts were imported into NVivo 11 qualitative analysis software (QSR International). An inductive content thematic method (Patton 2014) was used to analyse data.

In line with interface research methodology, methods to ensure Indigenous knowledge consideration and inclusion were engaged. As such, contribution was sought for data analysis from Author NK, an Aboriginal woman external to the main project, yet linked closely to the main researcher through a cultural mentorship role. Consistent with the coming together of Indigenous and Western knowledge, these processes contribute to reliability of data analysis and demonstrate our application of interface research methodology.

Results

In the data from the overall study, 76 participants described burns care as being delivered by multidisciplinary teams via three main care modalities: inpatient, outpatient and telehealth, or by a combination of these modalities. Burns units were described as being resourced via activity based or state government health funding, and availability of resources and specific service environments dictated aspects of care. Subsequently, aspects of care differed between units, for example the utilisation of anaesthetic services in outpatient care settings and the availability of play therapists. Communication within teams was often directed through lead burns nurses within hierarchal team structures. Client care was reportedly enhanced through discussion of individual cases in multidisciplinary team meetings. Participants identified that evidence, resources and resourcing, decision-making processes and values and beliefs informed the provision of burns care for Aboriginal and Torres Strait Islander children and families in Australia. This paper reports on the findings from the interview question regarding differences in care for Aboriginal and Torres Strait Islander children.

Participant reports of care that is different (*or not*) for Aboriginal and Torres Strait Islander children and families than for non-Indigenous children were categorised into three main groups. Group 1 – those participants who identified the need for different care; Group 2 – those who seek the same care but deliver different care; and Group 3 – those who value the same care above all (Table 10).

Table 10 - Summary of results

	n (overall study)	*n* (asked if care is different)	Attended cultural competency training	Results Group 1	Results Group 2	Results Group 3
Nursing	20	20	20	9 (45%)	6 (30%)	5 (25%)
Medical	16	15	8	4 (27%)	2 (13%)	9 (60%)
Allied health	28	27	25	17 (63%)	5 (19%)	5 (19%)
Administrative	4	3	3	3 (100%)	-	-
A/ILO	7	0	not asked	not asked	not asked	not asked
AHP	1	0	not asked	not asked	not asked	not asked
TOTALS	76	65	56	33 (51%)	13 (20%)	19 (29%)

Group 1 - Identified the need for different care

More than half of the participants (33/65) described provision of different care for Aboriginal and Torres Strait Islander children. *'…there are some changes to our practice…because that's more appropriate that you do that'* (4.07). Notwithstanding variations in wording, there was conceptual consistency in the descriptions of different care that resulted in 15 examples of different care being provided (Table 11). Many of the participants in this group responded assertively with words like '*absolutely'* and '*definitely'*. Of the 27 allied health participants, including all interviewed social workers and psychologists, 17 responded affirmatively to the provision of different care.

There was broad consensus across specialties regarding the engagement and involvement of A/ILOs as an example of different care for Aboriginal and Torres Strait Islander children and families. One participant said that including the A/ILO in care was about '…*ensuring the right people at the right time in the right space to deliver the right care is also about including those key people*' (3.02). Very few participants talked about their involvement in case conferences or participation in relevant burns team meetings. When geography was considered by this group as leading to the provision of different care, it was about understanding the socio-economic context in which the family live and being respectful of their Country. Participants also described providing different care based on the importance of family. This meant '…*including the family as a unit rather than directly working with maybe one parent*' (2.15) and '…*allowing time for patients to go back and discuss matters with family which might not in other situations be needed*' (4.07). Consideration of '…*the dislocation* [from family] *in Indigenous is something that we have to be much more aware of*' (5.04) was described by one participant when talking about the provision of different care based on family.

Decisions regarding discharge (*or not*) of Aboriginal and Torres Strait Islander children and families from tertiary care were different when compared to non-Indigenous children and included consideration of geography, infection, perceptions of compliance with care and prevalence of co-morbidities. This was summed up by one participant as:

> *I always lean towards keeping them kids in longer…we just don't know a lot of the time about what environment, it's so multifactorial…I suppose sometimes I feel that if we can keep them here, keep them really well nourished, keep their dressings clean and all the rest of it, then we might sort of limit a lot of the long term complications but that doesn't necessarily always happen because there's always a push for beds and strictly speaking they don't need to be here (4.05).*

Different care was provided to Aboriginal and Torres Strait Islander children and families in relation to communication, language and understanding. Participants said it was important to '…*listen to the whole story because management might change if I know where they're from and how they live*' (4.03). Furthermore, participants said they engage interpreters (3.02, 3.05, 3.09, 3.15, 4.06, 5.06), don't assume knowledge (4.03) and use different concepts to enhance understanding about care (3.15, 3.08, 5.06). A smaller number of participants also described changing their practice to be more culturally cognizant. For example, one social worker said:

> *…so from the moment when you walk in the room if it is an Indigenous family you're thinking am I being culturally sensitive, am I being culturally appropriate to this family's needs, having that in the back of your mind…just making sure you're aware of that' (5.07).*

Despite not being asked, participants also described understanding one's own biases, having an awareness of the incongruences between the ways of Aboriginal and Torres Strait Islander families and that of the Australian health system, and knowledge of identified risk factors as reasons *why* they provided different care. In terms of biases, participants described understanding their own culture, knowledge (*or lack of*) and preconceived ideas about Aboriginal and Torres Strait Islander people led to the provision of different care. One nurse described her own ignorance regarding language when providing care to a family.

> *English isn't his first language so his dad needs to interpret what we're saying and what he's saying to us and I think that's something that I've taken for granted because actually I see a little person who is Aboriginal and I think they're absolutely going to speak English…that's my own ignorance (3.02).*

The incongruences between the ways tertiary health settings are structured and operate and the ways of Aboriginal and Torres Strait Islander peoples were described by participants who also talked about understanding history and its impact: '…*historically Aboriginal people are much more guarded and don't really like to open up as much with government services'* (5.10). Furthermore, '*European culture is very structured and doesn't fit necessarily so it can be a mismatch on how to provide care*…' (5.08). Participants also described confronting dominant structures like a large tertiary health service as daunting: '…*this is a really foreign and scary environment…*[their lives don't] *often fit with the way wards are managed*…' (5.08) and a reason for the provision of different care. Understanding differences in priorities were also given as a reason for the provision of different care. For example, one participants said that '…*being aware that their reasons for not attending may not be good enough for us but it is good enough for them*' (6.02). Understanding the challenges, such as the increased incidence of other conditions, '…*so while they're here it is an opportunity to make sure they get an ENT review*…' (5.04) and associated risk factors for

Aboriginal and Torres Strait Islander children and families also accounted for the provision of different care.

Group 2 – Seek the same care, but deliver different care

One fifth (13/65) of participants said they did not provide different care for Aboriginal and Torres Strait Islander children and families. However, it was with less conviction than those participants who said they did provide different care and they also proceeded to describe examples and circumstances of different care (Table 11).

> *I think we treat everyone fairly equal, the only thing that I think that we would maybe do differently is getting the ALO involved a bit more with the families from a social work point of view, but other than that I can't really think of anything (2.06).*

More than half of this group of participants (1.09,1.10, 2.06, 2.08, 2.14, 4.08, 6.06), after saying no to the provision of different care, said they do engage the A/ILO if a child identifies as Aboriginal and Torres Strait Islander. This was said to be because they '…*make sure that the ALO are aware that the family is here because that's very important to draw that family support again for them and obviously link up with their family groups that might be here*…' (1.09).

Other instances of different care, similar to those described by participants in Group 1, include consideration of geography in terms of access to food following discharge (1.08), responding to gender differences for cultural reasons (1.11), engaging interpreters (4.08), providing extra attention for follow-up care (4.02) and engaging in more applicable conversation relative to cultural background (2.12). One participant said '*I think the only thing we probably tolerate a little bit or are a little bit flexible with is time*' (2.11), while another said family commitments were considered. 'There have been instances where we've probably pushed to get them home quicker than what we might normally do for other families because they're from a distance and have a lot of other family members at home needing them, that's probably a big one' (6.03).

Some participants in this group expanded on seeking equal care, yet providing different care for Aboriginal and Torres Strait Islander children and families. When talking about being culturally respectful, one participant said '*the intervention essentially is typically the same but it's about how we modify the delivery*' (6.06). Another participant said when describing how they refer to local Aboriginal health services for support with follow-up care:

> *…I don't think we individualise and it would be wrong to say that there's an overall policy difference between Aboriginal and Torres Strait Islander and non-Indigenous people and I think we like to think that each individual gets as much or as little care as they need (2.08).*

Table 11 - Examples of provision of different care

Group 1 – *Identified the need for different care and provided examples*
Engages and involves A/ILO
Considers geography in relation to understanding welfare, being respectful of Country and the use of telehealth
Considers appropriate food in health service
Considers and responds to gender needs
Shares information with local and already engaged services
Understands difference in the importance of time and is flexible with appointments
Considers family in relation to importance; contribution to care; other commitments; inclusion of extended family in decision-making; kinship and advocacy
Makes different discharge decisions based on geography; risk of infection; inability to adhere to care regimes or recognise infection; increased risk of scarring and higher prevalence of other chronic conditions
Considers that needs outside of the hospital environment still need to be met and making allowances for care
Develops and uses Indigenous-specific and appropriate resources
Considers communication in relation to understanding and language; engages interpreter; does not assume medical knowledge or health literacy; spends time listening and hearing whole story and uses different language and different concepts to enhance understanding
Spends time building relationships and rapport
Understands opportunistic care and facilitates access
Considers and practices in culturally appropriate and sensitive ways
Uses a holistic approach
Group 2 – *Seek the same care, but provided examples of the delivery of different care*
Engages A/ILO
Consideration of gender
Engages interpreter
Refers back to local Aboriginal health service
Provides extra support with follow-up
Tolerates time considerations and is flexible
Engages in applicable conversation
Considers family commitments at home
Considers geography in relation to access to food
Considers garment colour choice
Tap into local resources
Is culturally respectful

Group 3 - Value equal care

Almost 30% (19/65) of participants reported the explicit intent and provision of the same burns care for Aboriginal and Torres Strait Islander children in comparison to non-Indigenous children. These participants valued things like geography, skin pigmentation, socio-economic status and developmental age as reasons for the provision of different care; not Aboriginality. Of the 19 participants who reported valuing equal care, nine were medical participants, accounting for 60% (9/15) of all medical participants asked about the provision of different care for Aboriginal and Torres Strait Islander children.

The majority of participants in Group 3 (8/19) reported geography as a compounding factor to the provision of different care as opposed to Aboriginality and was demonstrated by one participant who said: '*No. I think remoteness is more important*' (4.09). Another participant answered by saying:

> *I think overall for better or for worse there's no difference...to be honest, usually more of the issues relates to geography and logistics and that's the same whether you are of Aboriginal and Torres Strait Islander descent if you live in the remote location or you're not of Aboriginal, you know it's just a remote location… (2.07).*

One allied health professional and one medical participant explained that they did not provide different care for Aboriginal and Torres Strait Islander peoples, however they did for patients with darker pigmented skin. Another two participants said they considered different care based on socio-economic status, while one other considered developmental age in regards to the provision of different care for different people, not Aboriginality.

For six participants, the provision of the same care for all patients was unequivocally important. These participants said '*no*' to the provision of different care for Aboriginal and Torres Strait Islander children and families.

> *'To be honest I couldn't care less about their status because we're treating them all the same and if they've got special requirements then you know we do that for every patient as we don't have a different pathway for Indigenous children' (6.07).*

Discussion

Multidisciplinary burns team members' demonstrated variable willingness and understanding of the need to provide different burns care for Aboriginal and Torres Strait Islander children and families. While the language of equity and equality was mostly missing altogether in the data, the processes that some participants described when communicating different care is in line with an understating of equitable healthcare(Whitehead 1991). Data from Group 1 and Group 2 suggested that the approaches taken by multidisciplinary paediatric burns teams in Australia more often than not reflect aspects of equity; indicating engagement in quality healthcare practice (ACSQHC 2010) and progression towards professional cultural competency (Bainbridge et al. 2015). Group 2 data also showed there is confusion over the constructs of equity and equality and how these might be operationalised in practice. This coincided with some unease regarding the provision of different burns care based on Aboriginality, grounded in participant's desire to do everything the same and aligning oneself within a domain of equality; yet seeking ways to address the needs of Aboriginal and Torres Strait Islander children and families. Data from Group 3 in this study also indicated the ideals and subsequent practice of some healthcare professionals are embedded solely in notions of equal care, indicating that there is a need for cultural safety education that explicitly examines the disjuncture in knowledges and the impact on healthcare outcomes.

Quality burns care

High quality care is care that is consumer centred, uses evidence, and is safe (ACSQHC 2010). Such focus on consumer centredness implies healthcare is equitable (Whitehead 1991). Data in this study showed the majority of burns care clinicians do regard context in the delivery of burns care for Aboriginal and Torres Strait Islander children and families. The provision of 'different' care was the result of an awareness of health outcome inequities and social determinants of health. Such healthcare practice is considered high quality (Whitehead 2010) and is reflective of enhanced cultural competency(9). However, while high quality and specialist multidisciplinary burns care is required for the best health outcomes following a burns injury (Al-Mousawi et al. 2009), high quality for Aboriginal and Torres Strait Islander children is only sometimes being realised through the receipt of healthcare that is relative to their cultural contexts.

Conflation of constructs

There is conflation in the constructs of equity and equality by burns team members as it relates to the provision of care for Aboriginal and Torres Strait Islander children and families. This is not surprising considering the differences amongst definitions across the literature. While clinicians in this study did not use the distinct language of *'equity'* or *'equality'*, some understand that they need to provide different or equitable care for Aboriginal and Torres Strait Islander children and families; at the same time considering they are doing things the same or providing equal care. The disjuncture (Durie 2005) between the biomedical model and the health and healing constructs of Aboriginal and Torres Strait Islander peoples is evident. Clinicians' reports for striving for equal care with limited understanding or consideration of equitable care, is clear evidence of the disjuncture here. Engaging in education around cultural safety to address this conflation may support members of burns teams in enhancing their understanding, and thus their cultural competency, around the necessity of providing equitable healthcare (Taylor & Guerin 2014).

Accepting discomfort through reflexivity

Issues of discomfort for healthcare professionals arose in this study upon realising that the results of their standards of excellence are not being equally realised. These issues are explicit in the results when presenting data about Aboriginal and Torres Strait Islander health issues. An opportunity exists for clinicians to address this discomfort (Wilson 2014) through engagement in reflexivity. Reflexivity has been used in research for the critical reflection of oneself in order to gain insight into one's own values and beliefs (Wilson 2014) and is key to cultural safety (Taylor & Guerin 2014). However, and similar to data in this study, evidence of how reflexivity is actualised in practice is limited, and is not supported in documents guiding burns care (Fraser et al. 2018); as such, limiting the ability of healthcare for Aboriginal and Torres Strait Islander children to be equitable. Wilson (Wilson 2014) suggests engagement in reflexivity may support healthcare professionals to become aware of the limitations of their practice, of which they are often unaware, and to develop new insight (Wilson 2014). Such insight might be that clinical expertise needs to include cultural competency for it to be experienced as best quality burns care by Aboriginal and Torres Strait Islander children and families.

Challenging the status quo

An equity approach to healthcare is the provision of care that is regardful of culture and challenges the status quo of providing care that is regardless of culture(2). Some data in this study showed there is little insight into the need for culturally competent care to address health inequities when participants reported treating everyone equally. Scientific measures for burns care are well reported in research literature (Kim, Martin & Holland 2012) and are important for best outcomes. However, the scientific evidence informing the normative approach to healthcare in Australia, ie the Western biomedical model, does not necessarily support or maintain an equity approach to healthcare with regards to Aboriginal and Torres Strait Islander peoples (Taylor & Guerin 2014). This assertion of superiority of world views (Durie 2005), conscious or otherwise, contributes to the unrecognised and ingrained lack of insight into equity in the delivery of burns care by some clinicians in the multidisciplinary burns team. The support of equality at the expense of equity in this study reflects the disjuncture of knowledges between the Western biomedical model and Aboriginal and Torres Strait Islander peoples constructs of health and healing. An equitable approach to healthcare is one that interfaces both knowledge systems (Durie 2005), highlighting a need for cultural safety education that explicitly examines the disjuncture in knowledges (Taylor & Guerin 2014) and the impact on inequitable burns care outcomes. Support by the healthcare system to facilitate reflexive practice and support for individual practitioners to engage with these opportunities for reflexivity is required.

Strengths and Limitations

This is the first study to investigate the constructs of equity and equality in burns care for Aboriginal and Torres Strait Islander children and families from the perspectives of multidisciplinary burns teams in Australia. We did not explore why clinicians did or didn’t do things differently for Aboriginal and Torres Strait Islander children and families, however many participants offered insight into why (*why not*). Not all of the people employed and working within burns teams were interviewed due to unavailability and the researcher being onsite for one week only. However, the collection of a large amount of qualitative data from on-site face-to-face interviews with a broad range of professionals in the burns team enabled everyday practices to be comprehensively explored. Drawing on recruitment across multidisciplinary burns teams increased the likelihood that all professions involved in the care of Aboriginal and Torres Strait Islander children and families were represented. As data collected were from burns team members only, and did not include the viewpoints of families receiving care, the ability to understand how children and families feel about the burns care they receive was a limitation of the study. Such data are being collected by other members of the research team and will provide some insight into patient and family experiences. Data collection with clinicians was enhanced by the principal researcher being a registered nurse with a thorough understanding of health systems and processes. As the research was about health and healing for Aboriginal and Torres Strait Islander children, the process was potentially limited because the principle researcher was a non-Indigenous healthcare professional primarily educated within a medical standpoint. This limitation was purposely addressed through Aboriginal oversight and involvement in research process, data analysis and reporting.

Conclusion

We found that burns care in Australia for Aboriginal and Torres Strait Islander children and families was predominantly delivered by clinicians who consider the need for equitable care. The ability to provide equitable care is sometimes limited by healthcare systems and by social determinants of health that are not within the treating clinician’s control. When there is no consideration of the need for different burns care for Aboriginal and Torres Strait Islander children and families, the full potential of its capacity to be best quality burns care for, and experienced as culturally safe by Aboriginal and Torres Strait Islander children and families, is limited. Furthermore, basing quality solely in terms of biomedical outcomes, is against current notions in high quality healthcare.

Chapter summary

In this chapter I presented findings from a subset of multidisciplinary burns team data. Findings show there is tension over the need to provide different burns care for Aboriginal and Torres Strait Islander children and families. As such, there was limited understand of equitable care in addressing disparities in health.

CHAPTER 10 – Formative evaluation of a patient journey mapping tool to investigate quality and cultural safety in burns care for Aboriginal and Torres Strait Islander children and families

The work presented in this chapter is in manuscript form and has been submitted for publication in *BMJ Quality and Safety.* The manuscript was submitted in March 2019 and is currently under review. This manuscript presents the methodology and methods behind developing a patient journey mapping tool to investigate quality in burns care for Aboriginal and Torres Strait Islander children and families. Appendices 13-17 include the relevant consent forms, participant information and interview guides.

Citation

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Attribution of Authorship

Authors SF, JG, TM, KH, JK and RI all contributed to the conception and design of this manuscript. Data collection was completed by SF and Aboriginal researcher Courtney Ryder. Analysis and interpretation of research data was performed by SF and contributed to by authors JG, TM, KH, JK and RI. Drafting of the manuscript was completed by SF, and revision of significant parts of the work so as to contribute to the interpretation was contributed to by SF, TM, JG, KH, JK, AH, BG, KC, WT, AD and RI.

Introduction

Significant focus and effort are being directed towards ensuring quality healthcare worldwide (Hayes, Batalden & Goldmann 2015). In Australia quality standards and accreditation measures (The Australian Council on Healthcare Standards) influence care provision and regulate healthcare efficiency and effectiveness. Engagement in quality improvement (QI) supports healthcare services and providers to constructively critique the healthcare they provide and engage in improvement activities (Hayes, Batalden & Goldmann 2015). Often improvement is focused on the performance and limitations of healthcare services, with process mapping and clinical redesign as QI methods

(Ben-Tovim, Dougherty, O’Connell et al. 2008, Johnson, Farnan, Barach et al. 2012). However, these methods often overlook patient experiences, with efficiency processes not always enhancing patient experiences or improving health outcomes.

In Australia, quality healthcare for Aboriginal and Torres Strait Islander peoples has increasingly been linked to the cultural competency of healthcare services and providers (Commonwealth of Australia 2013, Bainbridge et al. 2015) and cultural safety (Laverty, McDermott and Calma 2017). The revised National Safety and Quality Health Service standards (ASQHC 2017) for health services now include six actions specific to the health of Aboriginal and Torres Strait Islander peoples’ and the cultural competency of tertiary healthcare services. It is increasingly recognised that quality healthcare must consider both cultural (Taylor & Guerin 2014, Best & Fredericks 2017) and clinical safety, ensuring that all needs of an individual and family are met. This concept is supported by the Australian Safety and Quality Framework for Health Care (ACSQHC 2010) which positions consumer centeredness as one of three key indicators of quality. Quality and safety for Aboriginal and Torres Strait Islander patients is inextricably linked to family, culture and Country. Thus, without a focus on cultural competency, quality of care is compromised (Laverty, McDermott & Calma 2017).

Evidence shows that Aboriginal and Torres Strait Islander peoples cannot reliably access healthcare that meets all their needs (Cunningham 2002, Dwyer, O'Donnell, Willis et al. 2016), suggesting deficits in quality. Experiences of being judged, misunderstandings and stereotyping of Aboriginal and Torres Strait Islander peoples within Australia’s mainstream healthcare system lead to distress and disengagement (Larson et al. 2007). Further, communication breakdown in the healthcare environment results in difficulty assessing symptoms, eliciting signs, reaching accurate diagnoses and providing effective care (Artuso et al. 2013). Together, these quality deficits contribute to inequitable health outcomes for Aboriginal and Torres Strait Islander peoples.

Aboriginal and Torres Strait Islander children experience burn injury at disproportionally higher rates than non-Indigenous children, resulting in tertiary healthcare and longer lengths of stay (Möller et al. 2017). Therefore, it holds that issues of healthcare quality may arise for this population. Furthermore, the models currently informing burn care worldwide do not meet all indicators of quality or cultural safety for Indigenous people (Fraser et al. 2018). While accreditation processes seek to ensure quality healthcare in tertiary settings (The Australian Council on Healthcare Standards 2019), including those with specific cultural competency (ACSQHC 2017) and burn care (American Burn Association 2017) components, a single tool that specifically assesses both the clinical and cultural quality of burn care for Aboriginal and Torres Strait Islander children and families is lacking. This paper describes a modified patient journey mapping (PJM) tool developed in the Managing Two Worlds Together (MTWT) Project (Kelly, Dwyer, Mackean et al. 2018), and testing of this tool, underpinned by interface research methodology (Durie 2004, 2005) to map and critique quality in the burn care journey of Aboriginal and Torres Strait Islander children and family.

An overview of PJM methodology and the theoretical context

Patient Journey Mapping

PJM is a quality assessment method used to better understand and provide a detailed account of patient healthcare journeys (Kelly, Wilden, Herman et al. 2016, McCarthy, O'Raghallaigh, Woodworth et al. 2016).. It provides a mechanism for identifying gaps and facilitating improvements in patient journeys by depicting the complexities inherent with healthcare, with a focus on QI (Kelly et al. 2016). PJM has previously described the journey stages in which the healthcare system fails or succeeds to provide quality and responsive care to patients, and is therefore a useful method to appraise and guide organisations' approaches to care (Ben-Tovim et al. 2008, Johnson et al. 2012). PJM highlights barriers and enablers to care from the perspective of both the recipient and provider of healthcare (Ben-Tovim et al. 2008, Kelly et al. 2016). Importantly, PJM enables comparisons of critical points in time with existing best practice models and guidelines.

Biomedical burns care

Improvements in burns care, including first aid, access to specialist services, and enhanced medical care have led to significant reductions in mortality and improved quality of life (Smolle et al. 2017). Furthermore, clear indicators of quality now exist regarding first aid, fluid resuscitation and wound management (Australian and New Zealand Burns Association , Ahuja, Gibran, Greenhalgh et al. 2016, American Burn Association 2017). While most serious burns require ongoing access to specialist care over months to years, knowing how best to provide such care for Aboriginal and Torres Strait Islander patients has not been fully explored (Ivers et al. 2015). Additionally, aside from asserting the importance of multidisciplinary care, evidence to inform incorporation of holistic care and cultural components of health and healing in burn care is lacking (D'Cruz, Martin & Holland 2013). Current models of burn care inform how care is provided across different levels of the health system, document care pathways, determine multidisciplinary team member inclusion, include clinical care protocols and indicators for quality (Government of Western Australia 2009, ACI 2011, Women's and Children's Hospital 2014). The evidence informing these models of care is predominantly from a scientific biomedical perspective and does not consider the needs of Indigenous people generally or Aboriginal and Torres Strait Islander children and families specifically (Fraser et al. 2018).

Various factors must be considered when contemplating quality burn care, including access to specialist facilities, multi-disciplinary team constitution, critical points in care and the evidence informing care. Serious burns, including those involving joints or young children, typically require specialist tertiary healthcare (Kim, Martin & Holland 2012) In Australia, these specialist tertiary services are metropolitan. Burn care is best delivered by multi-disciplinary teams (D'cruz, Martin & Holland 2013) comprising many healthcare professionals, who each bring a unique skill set, focus and contribution to care. Key professions in these teams include: nursing; occupational therapy; physiotherapy; medical; dietetics; psychology; and social work (Government of Western Australia 2009, ACI 2011, D'cruz, Martin & Holland 2013, Women's and Children's Hospital 2014). Burn care can be separated into distinct critical points in time from a biomedical perspective, evident in the existing models that guide burn care (Government Western Australia 2009, ACI 2011, Women's and Children's Hospital 2014) and research evidence (Kim, Martin & Holland 2012).These critical points, whilst referred to differently, include: the injury; emergency care; ambulatory care; admission; in-patient care; discharge; and rehabilitation. Severity of burn injury dictates level of care accessed. Although the evidence-base varies for models of burn care used in Australia (Australian and New Zealand Burns Association, Government of Western Australia 2009, ACI2011, Women's and Children's Hospital 2014), commonalities in treatment exist across the models (Appendix 19).

<u>Health and healing constructs of Aboriginal and Torres Strait Islander peoples</u>

There are both fundamental commonalities and significant differences between Indigenous peoples in Australia, and internationally. A strong unity with the environment, holistic health constructs, experiences of colonisation and socio-economic disadvantage are often shared factors (Royal 2002). Expressions and experiences of healthcare, healing and culture may be unique between individuals, families and communities (Durie 2004). Concepts about rights and responsibilities for Aboriginal and Torres Strait Islander peoples in part relate to kinship and family (Franks & Curr 2007, Milroy 2008). For Aboriginal and Torres Strait Islander peoples, much emphasis is placed on the enduring connection with family and Country; keeping people strong and healthy both physically and culturally (Franks & Curr 2007, Purdie, Dudgeon & Walker 2010). Thus, the link between culture and health is significant. ‘Stories’ for Aboriginal and Torres Strait Islander peoples contain knowledge, and storytelling is a way to maintain and transmit knowledge (Martin 2003) often through yarning (Box 1) (Bessarab & Ng'andu 2010). Stories are imperative to eliciting patient experiences and perspectives of healthcare (Emden 1998, Kelly et al. 2012) and reflect the importance of knowledge as a whole (Muller 2014), as opposed to segregation into parts.

Box 1 - Definition of yarning

Yarning is an Indigenous cultural form of conversation and data gathering tool in research. It is where collaborative conversations occur and participants and researchers 'journey together'. Through use of the yarning method, participants remain relaxed; providing a space for rich dialogue.

Many Aboriginal and Torres Strait Islander peoples hold a holistic model of health and healing that is not fully responded to or always understood by Australia's dominant biomedical health system (Best & Fredericks 2017). The multi-dimensional holistic model includes considerations of physical, psychological, social health and wellbeing, spirituality, and cultural integrity aspects (Australian Indigenous Doctors' Association 2010). When cultural and spiritual aspects of health and healing are considered within the context of healthcare, health outcomes for Aboriginal and Torres Strait Islander peoples are improved, and an experience of culturally safe care is achieved (Laverty, McDermott & Calma 2017). The theory of cultural safety, originally developed in New Zealand (Ramsden 2002), has since been applied to healthcare in Australia (Taylor & Guerin 2014, Laverty, McDermott & Calma 2017). The principles of culturally responsive and respectful care have been adapted further, with implications for use in assessing quality in standards (Fraser et al. 2018) and Australian healthcare policy (Mackean et al. 2019). This includes the principles of reflexivity, dialogue, power imbalances, decolonisation and regardful care. While many providers in the Australian mainstream healthcare system endeavour to provide culturally competent healthcare (Bainbridge et al. 2015). It can be argued a lack of training, resources, knowledge or bias impairs their ability to achieve this competency.

Interface research methodology (IRM)

Western science, a dominant global knowledge system, is in stark contrast to Indigenous knowledge systems of knowing, being and doing (Martin 2003, Moreton-Robinson & Walter 2009). The ways of knowing, being and doing of Aboriginal and Torres Strait Islander peoples are holistic and linked to connectivity and relations with Country (Martin 2003, Franks & Curr 2007, Australian Indigenous Doctors' Association 2010, Purdie, Dudgeon & Walker 2010). Western knowledge systems are based on rational positivist theory (Martin 2003.) In Australia, the normative approach to healthcare, including burn care, is based on Western scientific knowledge known as the biomedical model (Best & Fredericks 2017). There are often contests about the validity of each knowledge system (Durie 2004, 2005). IRM bridges the divide between Indigenous and Western knowledge systems in a space without notions of dominance or superiority, whereby mutual respect, shared benefits, human dignity and discovery provide an opportunity for new and relative knowledge production for both paradigms (Durie 2004, 2005) This exploration and interfacing of ways of knowing, being and doing is the existing Ganma method (Pyrch & Castillo 2001) which aligns with IRM. As such, IRM creates an opportunity for guiding the development of a PJM tool for assessing quality in burn care in Australia for Aboriginal and Torres Strait Islander children and families.

Ecological modelling

Ecological modelling recognises that health and healthcare are influenced at different levels within complex health systems and can be used in planning healthcare, to illuminate the various levels embedded in a health system, all of which are interrelated and not independent of one another (Reilly et al. 2011). By considering QI tools with ecological frameworks, there is the potential to bring together, the: recipient of care; healthcare service; and healthcare system. This is important given interdependent factors informing burn care in Australia.

Methods to develop the modified PJM tool

The PJM tool was modified (Kelly et al. 2017) to provide five key components of quality assessment. Developing the PJM tool to map the healthcare journey of an Aboriginal and Torres Strait Islander child with a burn required consideration of an additional three components of quality (Box 2). The following sections describe the methods involved in developing the modified tool for burn care.

Box 2 - Components of quality and quality assessment

Five key components of quality assessment:

1. a method to capture the key elements of the burns care journey
2. quality components of the underlying existing approaches for burns care
3. healthcare provider and patient perspectives of burns care
4. the explicit aspects key to quality care for Aboriginal and Torres Strait Islander children and families
5. the relationships between these elements

Three relevant components of quality for Aboriginal and Torres Strait Islander children and families:

1. critical points in the burns care journey
2. existing models of care and best practice
3. holistic health constructs

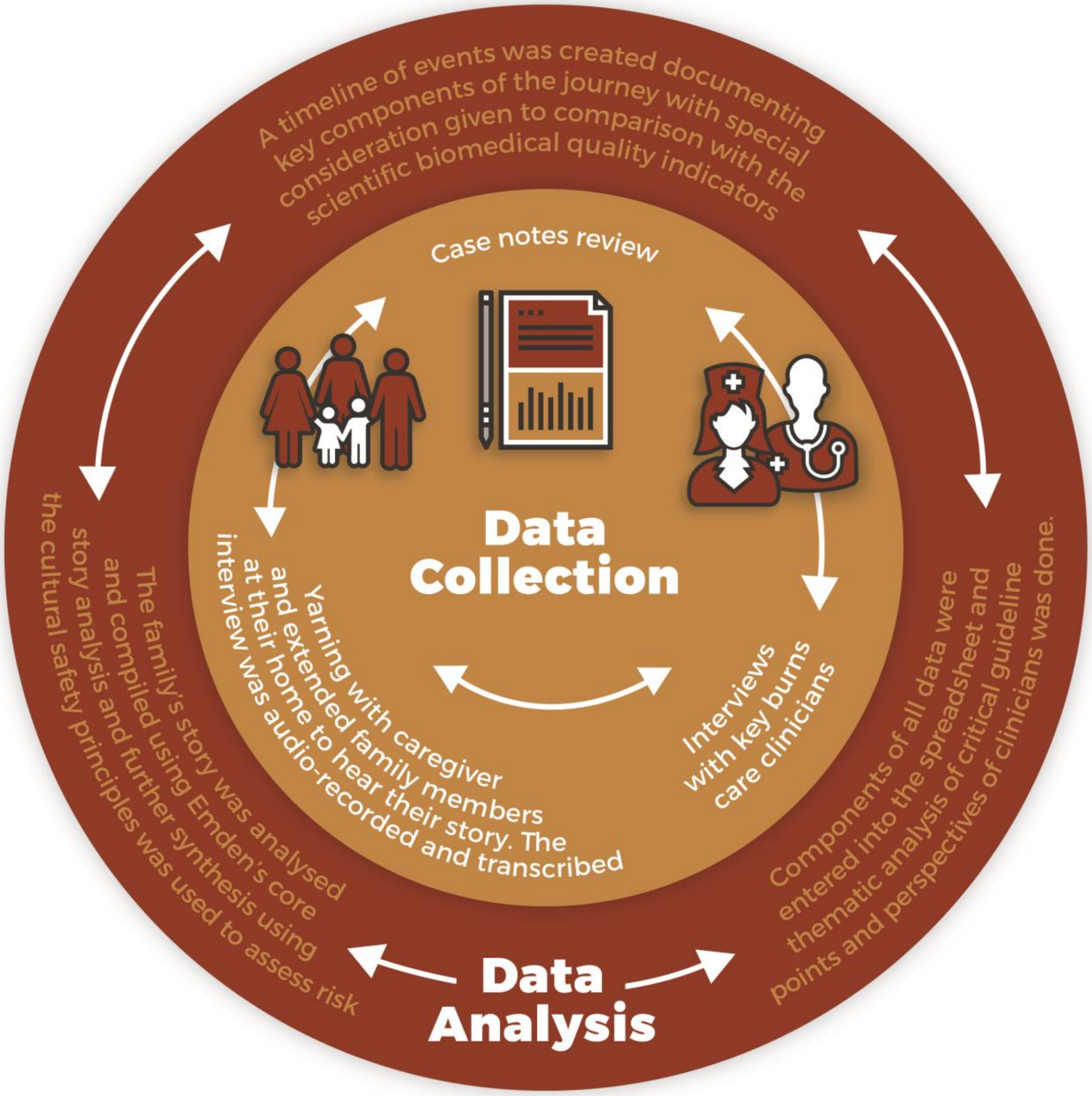
Input from clinicians and policy makers was sought to confirm the biomedical aspects of burn care (Australian and New Zealand Burns Association, Government of Western Australia 2009, ACI 2011, Women's and Children's Hospital 2014). These were incorporated throughout the tool for assessment of whether or not healthcare providers conform to the evidence underpinning medical aspects of burn care. The inclusion of these components aims to better elucidate enablers and barriers to the provision of quality care.

Consideration of the health and healing constructs of Aboriginal and Torres Strait Islander peoples was another key aspect considered in modifying the tool. Both theoretical constructs (Ramsden 2002, Durie 2004, Milroy 2008), and Aboriginal co-researchers contributed to knowledge of how these could be applied. Identification of how healthcare provides are/are not providing burn care that meets the needs of Aboriginal and Torres Strait Islander children and families with consideration of why/why not was incorporated through holistic philosophies (Milroy 2006) where the burn care stories of children and families were important. The critical time points of burn care for families were established through consideration at the interface of knowledges, albeit less rigid points than those associated with biomedical burns care.

The compilation of this information into a single PJM tool was facilitated by use of a single spreadsheet file with two components: one to document the scientific medical evidence (Appendix 18); a second to record the burn care journey in-line with Aboriginal and Torres Strait Islander constructs of health and healing (Table 12) and Appendix 20. A roundtable of researchers, clinicians and Aboriginal healthcare professionals critically refined the tool which facilitated use of thematic analysis (Patton 2015). Endorsement for the testing of the tool was sought and ethics was gained for the relevant tertiary health service.

An outer metropolitan family agreed to participate in the testing of the PJM tool. This participant, an Aboriginal child whose family accessed tertiary burn care, was chosen from an overarching study investigating burn injury in Aboriginal and Torres Strait Islander children (Ivers et al. 2015). The role of the main researcher testing the tool (author SF), was a PhD candidate, external to the tertiary healthcare site, yet linked to the site through their participation in the overarching study.(Ivers, Hunter, Clapham et al. 2015) The mapping process entailed four main stages, which were completed iteratively, but not sequentially (Figure 7). All data was de-identified to ensure anonymity.

Figure 7 - Data collection and data analysis mapping process



The evaluation of effectiveness of the PJM tool was based on a qualitative critical analysis of the process and outcomes of using the tool. The tool was critiqued by Author SF for its ability to assess quality in burn care, and how well it was able to elicit Aboriginal and Torres Strait Islander child and family components of quality care or lack thereof. The efficiency of the tool was measured against its ease of use as a QI tool in a tertiary healthcare setting.

Results

Effectiveness of the modified PJM tool in identifying in quality care

The PJM tool was able to identify where there are gaps in the healthcare system regarding quality of burn care for Aboriginal and Torres Strait Islander children and families. Burn care was mostly delivered in line with the prescribed indicators of biomedical quality; e.g. first aid was given, burn specialist assessment was within the stipulated time-frame and multi-disciplinary care was provided. However, contribution by the Aboriginal/Indigenous liaison officer (A/ILO) was both late and limited, and access to rehabilitation services outside of the tertiary healthcare environment was reduced and did not meet standards (Appendix 21). The family perceived that they experienced disrespectful care; they felt isolated as they felt helpless during their child's inpatient stay and vulnerable on discharge. The family also identified significant gaps relating to follow-up care and ease of access to rehabilitation. Mapping data also identified that healthcare providers were neither resourced nor supported to provide best care following patient discharge, and there were limited options for referral to community based social workers (Table 12). Synthesis of the narrative data (Appendix 22) identified that care was most likely experienced as culturally high risk at the sustained interface and going home phase (Table 13, Figure 8).

Testing of the PJM tool was undertaken over four months (approximately 120hrs) in 2018. The tool was lengthy and could be reduced by the inclusion of only those standards specific to the jurisdiction where the tool is being used. Testing of the tool with regional/remote families and with older children is required.

Table 12 - PJM tool Spreadsheet Two. Indigenous concepts of health and healing and family and healthcare professional perspectives

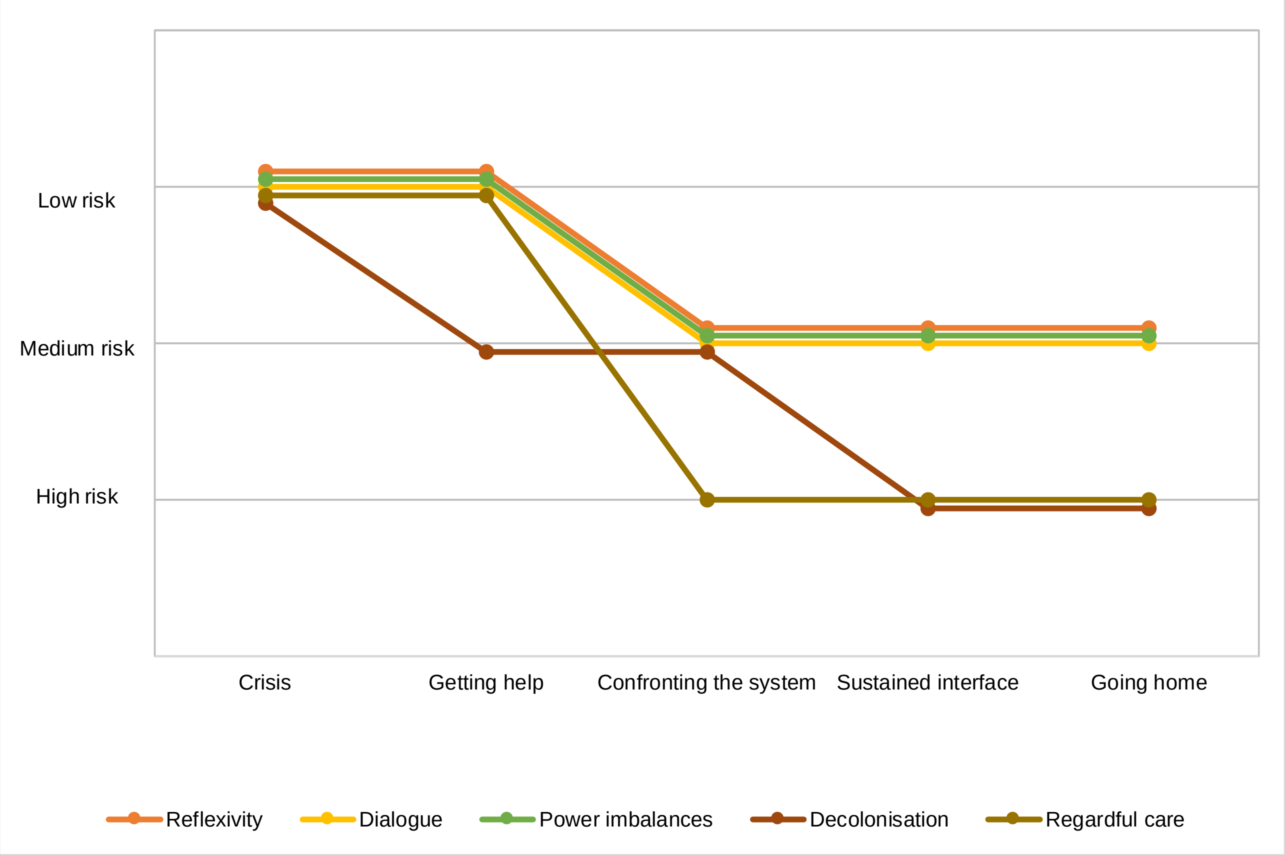
Points in time - headings to elicit holistic views of health	**Crisis**	**Getting help**	**Leaving competing obligations**	**Confronting the system**	**Sustained Interactions**	**Being away**	**Going home**	**Confronting competing needs**
Caregiver's perspective	Accessible and appropriate care.	Accessible and appropriate care.	Care arranged for sibling and family contacted.	Identification question asked. Felt scared and ignored. Social worker provided support.	Communication was inconsistent. Felt judged for not staying in the hospital. Unable to work with subsequent extreme financial pressure and no access to disability pension. Food vouchers infrequent and covered only very minimal amounts.	Difficult to find care for sibling. Increased burden on extended family for sibling care and visiting hospital. Sibling difficult behaviour. Financial support to cover part of fuel costs to drive to hospital each day. No PATS. Home bills left unpaid.	Felt pushed out. Discharged without confidence. Psychological distress.	Financial support to cover part of fuel costs to drive to hospital each day. No PATS. Unable to return to work for almost one year. Long appointments that meant whole day trips. Sustained burden on extended family for sibling care.
Child's perspective (6yo or >)	N/A as child <6yo	N/A as child <6yo	N/A as child <6yo	N/A as child <6yo	N/A as child <6yo	N/A as child <6yo	N/A as child <6yo	N/A as child <6yo
Referring Hospital/GP	N/A	Not able to speak to Ambulance worker. Case Notes: identification question asked.	Case Notes: consideration for care of sibling documented.	N/A	N/A	N/A	N/A	N/A
AHW	No AHW employed	No AHW employed	No AHW employed	No AHW employed	No AHW employed	No AHW employed	No AHW employed	No AHW employed
A/ILO	N/A	N/A	N/A	Not notified child was Aboriginal whilst in ED.	Supported family financially with fuel and food vouchers. Helped with access to hospital child care for sibling.	Not resourced to provide support care outside of the hospital or to those family outside of the hospital environment.	Arranged by burn team.	Not resourced to provide support.
Ngangkari (Traditional Healer)	Not requested by caregiver. ? availability.	Not requested by caregiver. ? availability.	Not requested by caregiver. ? availability.	Not requested by caregiver. ? availability.	Not requested by caregiver. ? availability.	Not requested by caregiver. ? availability.	Not requested by caregiver. ? availability.	Not requested by caregiver. ? availability.
Burn Nurse	N/A	N/A	Notified via pager. No support care provided.	Attended ED on arrival of family. Spent time with caregiver.	Time spent with caregiver M-F to ensure understanding. Made caregiver feel comfortable with environment.	Encouraged accessing extended family for support with sibling.	Provided written instructions. Gave some dressings.	Attempts to make dual appointments.

Points in time - headings to elicit holistic views of health	**Crisis**	**Getting help**	**Leaving competing obligations**	**Confronting the system**	**Sustained Interactions**	**Being away**	**Going home**	**Confronting competing needs**
				Provided caregiver with clothes to change in to.				
Occupational Therapist	N/A	N/A	N/A	Automatic referral received	Care provided in ICU	Attempts to make dual appointments.	Discharge advice given.	Attempts to make dual appointments.
Physiotherapist	N/A	N/A	N/A	Automatic referral received	Positioning in ICU	Attempts to make dual appointments.	Discharge advice given.	Seen in scar clinic.
Surgeon (medical staff)	N/A	N/A	N/A	Case Notes: Informed consent and surgical procedures.	Case Notes: Informed consent and surgical procedures. Allowed caregiver to give consent over the phone for second and subsequent procedures.	Case Notes: noted caregiver seen by social worker.	Case Notes: Medical review prior to discharge.	Case Notes: Wound and scar review as necessary.
Psychologist	N/A	N/A	N/A	Case Notes: no input into care	Case Notes: no input into care	Case Notes: no input into care	Case Notes: no input into care	Case Notes: no input into care
Social Worker	N/A	N/A	N/A	Supported and sat with caregiver in ED Explained situation. Explained presence of police officer and mandatory notifications	Supported caregiver with social health and welling. Ensured access to fuel and food vouchers.	Provide written evidence to support disability pension claim.	Ensured access to fuel vouchers.	Not resourced to provide support once discharged.

Table 13 - Narrative data synthesis of caregivers experience of culturally safe care and associated risk

Cultural safety principle	**Definition**	**In-Practice**	**Caregiver's experience at holistic time points and associated level of risk**				
			crisis	help	confront	sustain	home
Reflexivity	Reflect on practice, mutual respect.	Respectful interactions.	low	low	med	med	med
Dialogue	True engagement and consultation.	Build rapport and dialogue with family alongside consideration of kinship arrangements and decision-making structures, particularly as they relate to children.	low	low	med	med	med
Power imbalances	Minimise power differentials and maintain human dignity.	Including Indigenous health workers in multidisciplinary teams.	low	med	med	med	med
Decolonisation	Acknowledging the key role of colonising history in contemporary health outcomes for Aboriginal and Torres Strait Islander peoples.	Ensuring equity in healthcare to achieve equity in health outcomes.	low	med	med	high	high
Regardful care	Provide care that is regardful of culture and challenges the status quo of providing care that is regardless of culture.	Patient-centred care; where the context for the child and their family drives care decisions.	low	low	high	high	high

Figure 8 - Graphical representation of narrative data synthesis of caregivers experience of culturally safe care and associated risk



Discussion

These findings confirm that retrospective data is useful in assessing healthcare quality in patient journeys, as well as interactions between various components of quality in this setting. The PJM tool enabled assessment of performance, regulatory constraints and patient experience in tandem. Analysis of this data, using Emden's analysis method (Emden 1998, Kelly et al. 2012) and thematic analysis (Patton 2015) gave insight into the families' journey of quality in burn care. The tool also gave burn healthcare providers the opportunity to externalise and reflect on their capabilities and the care they provide. As a result, use of PJM provided a space for healthcare providers to consider how to improve and innovate within their own practice through reflexivity. While existing professional relationships with the lead burns nurse made access to relevant clinicians more successful due to this nurse's influence on facilitating clinician availability, it was sometimes difficult to engage busy clinicians with the mapping process when seeking to clarify and understand key points and interactions within the journey. This reflects findings of the MTWT Project, where clinician engagement was promoted by collaborative involvement in the research and development of tools, as compared with externally-developed tools imposed upon them (Kelly et al. 2017) Therefore provision of more information on the processes and aims of PJM may enhance participation by busy clinicians.

Recruitment and engagement of family members in mapping was enhanced by existing relationships with the mother. Having the grandparents present at the family interview contributed to a deeper understanding. The family interview was facilitated with an Aboriginal woman as a co-researcher, supporting ethical research. The interview was conducted in the family home, on the basis the family were more likely to feel secure in their own space, and dinner was supplied though study funds.

This test did not include responding to the findings to improve communication, reduce perceived differential treatment or enhance access to post-discharge care. Further considerations need to be made to determine how best to work with multidisciplinary burns teams and healthcare services to effectively plan and implement improvements in burn care for Aboriginal and Torres Strait Islander children and families. Existing QI frameworks and engagement in reflexivity by healthcare practitioners may be key aspects of future approaches.

Conclusion

The PJM tool aims to facilitate the exploration of complex patient journeys following a burn injury, increasingly knowledge of what works well and what needs improvement in the healthcare system for Aboriginal and Torres Strait Islander children and families. Whilst many methods and philosophical approaches to improve the quality and safety of healthcare exist, most neither address the interface of Indigenous and Western biomedical knowledges, nor provide opportunity for children to have a voice. In undertaking this study, we have developed a tool enabling research of burn care quality at the interface between existing biomedical models of care, and more holistic, fluid and culturally safe models of health.

Chapter summary

In this chapter I have described how PJM enabled deeper exploration of complex patient journeys and is an effective mechanism for focused quality improvement activities. Based on our evaluation of the tool, it can serve to improve quality, and identify specific aspects of culturally safe care of Aboriginal and Torres Strait Islander peoples. In the next chapter, I bring the findings of all research components together within a discussion including recommendations.

CHAPTER 11 – Bringing it all together

In this chapter I present a summary of the research findings presented in this thesis and their implications for burns care for Aboriginal and Torres Strait Islander children in Australia. In doing so I provide a critique of the findings aligned with those theories and practices relative to good health and healing for Aboriginal and Torres Strait Islander children and families. Recommendations arising from the research and implications for translation into practice are stated throughout the chapter at the end of discussion sections. This is followed by a concluding statement about the research.

Summary of key findings and contributions from this research

This thesis is unique in that it is the first known published body of work to focus on the structure and provision of burns care for Aboriginal and Torres Strait Islander children and families in Australia. The research involved a systematic exploration of burns care delivered by multidisciplinary burns teams from tertiary health services across Australia. The research identified specific issues of quality in burns care for Aboriginal and Torres Strait Islander children and families. Importantly, through the research I demonstrated that there is opportunity for interfacing Aboriginal and Torres Strait Islander people's knowledge with Western biomedical knowledge in research; as is the case for the delivery of healthcare.

The work was informed by clear inequities in both prevalence and access to care for burns injury for Aboriginal and Torres Strait Islander children (AIHW 2011b, Möller et al. 2017). In recognition of the over-representation of Aboriginal and Torre Strait Islander children in burn injury, an exploration of current burns care in chapter three identified differences in care outcomes and a lack of clarity about how current burns care meets the needs of Aboriginal and Torres Strait Islander children and families. My first systematic review in chapter four showed that telehealth as a modality of care may improve access to healthcare for those families living in regional or remote locations, however the cultural competency of telehealth remains unclear (Fraser et al. 2017). In addition, the second systematic review presented in chapter five identified that existing models of care for burns injury do not meet all aspects of quality or cultural safety (Fraser et al. 2018). Overall, I identified a disconnect between Western and Indigenous knowledges. This disconnect is manifest in both Australia's mainstream healthcare system and in the documents that inform burns care.

Results from interviews with multidisciplinary burns teams presented in chapter eight showed burns care is informed by multiple factors, including evidence, resources and resourcing, decision-making processes and values and beliefs. Imbalances of power and the perpetuation of colonisation, through hierarchal teams and the dominant use of the biomedical model, were evident throughout. It is important to note that the use of the biomedical model is necessary and appropriate for medical interventions, but falls far short when applied uncritically to cultural components of care, where alternate ways of enacting care are required (Mackean 2009, Taylor & Guerin 2014, Laverty, McDermott & Calma 2017). This is because the biomedical model is based on scientific evidence, which segregates the body into parts and disregards other health paradigms (Best & Fredericks 2018). The sole use of the biomedical model means that equity in healthcare is limited because there is restricted capacity for the delivery of care based on needs other than those aligned with this model. This restricted capacity was echoed in the findings from a subset of multidisciplinary burns team interview data. These findings were presented in chapter nine where multiple issues related to equity and equality in the delivery of burns care for Aboriginal and Torres Strait Islander children were identified. These included a limited understanding of the need to provide different care for Aboriginal and Torres Strait Islander children and families, and little or no use of reflexivity in practice. Lastly, the research has resulted in the development of a platform to better understand and assess quality and cultural safety in burns care through patient journey mapping as was presented in chapter 10. Overall, findings from this research showed that issues of quality in burns care for Aboriginal and Torres Strait Islander children and families relate primarily to: 1. a dominant use of a Western biomedical paradigm; 2. tension over the need to provide different care for Aboriginal and Torres Strait Islander children and families; and 3. limited formal use of reflexivity in practice.

I present these findings below within a discussion of good health and healing for Aboriginal and Torres Strait Islander children and families in the context of cultural safety. This discussion will synthesise the research findings and provide a foundation for recommendations for the improvement of care that account for the disjuncture of knowledges and works towards reducing it. This will lead to a better understanding about how multidisciplinary burns team members, and the structures in which they function, are able to know, accept and reflect on best quality care for Aboriginal and Torres Strait Islander children and families to improve health outcomes. These enhanced understandings will contribute to informing a new model of care for burns. I start by defining the overall issue of quality in burns care for Aboriginal and Torres Strait Islander children and families and position this discussion within a space of opportunity for change.

An overall issue of quality

This work has established that the full potential of paediatric burns care in Australia is limited in its realisation for Aboriginal and Torres Strait Islander families accessing care. This is an issue of quality concerning the provision of care for Aboriginal and Torres Strait Islander children and families for which there are implications as a direct result of not achieving best quality burns care. Data from this research showed that issues of quality relate primarily to: 1. a dominant use of a Western biomedical paradigm; 2. tension over the need to provide different care for Aboriginal and Torres Strait Islander children and families; and 3. limited formal use of reflexivity in practice. Such results mean burns care is limited in its ability to be experienced as culturally safe by Aboriginal and Torres Strait Islander children and families (Laverty, McDermott & Calma 2017).

The dominant use of a Western biomedical paradigm (Laverty, McDermott & Calma 2017, Best & Fredericks 2018) was first found in the context of this thesis through the exploration of existing research evidence regarding burns care. The uncritical use of telehealth as a modality to care for Aboriginal and Torres Strait Islander peoples without cultural considerations demonstrates the dominance of the Western biomedical paradigm (Fraser et al. 2017). When critiqued for cultural safety (Taylor & Guerin 2014), there was limited evidence of engagement with the principles of cultural safety in the existing burns injury models of care (Fraser et al. 2018). As such, the models were found to be predominantly focused on and developed within the biomedical paradigm. The dominant use of the biomedical model was also evident in what multidisciplinary burns team members described as guiding care and in the descriptions of their practice.

The dominance of the Western biomedical paradigm meant there was tension and a lack of understanding over the need to provide different care for Aboriginal and Torres Strait Islander children and families. This was evident in the findings of the review of burns injury models of care whereby the evidence in the models showed limited engagement with cultural safety. This was further demonstrated by little to no evidence in the documents emphasising the necessity for regardful care. Furthermore, evidence in the multidisciplinary burns team data showed there was a tension around the need for and provision of different care. As a result, much of the descriptions of care didn’t account for equity.

The dominance of the Western biomedical paradigm and limited understanding of the need to provide different care for Aboriginal and Torres Strait Islander children is indicative of limited engagement with formal reflexivity in practice by multidisciplinary burns teams. The use of telehealth as a modality for care without consideration of culture is one example. The models of care, found to be limited in their ability to inform care that incorporates reflexivity is another example. Furthermore, there was very limited discussions about engagement in reflexivity and reflecting on their care by healthcare providers when describing their practice.

Opportunities for challenging the status quo exist

It was very clear from this research that there was dominant use of the Western biomedical model in the enactment of burn care. There is limited or no reflexivity evident in burns care for Aboriginal and Torres Strait Islander children and families, and there is limited understanding of equity and equality or the realisation that the Western biomedical paradigm will not solve everything for everyone because it is generally regarded as the only approach to delivery of care. However, there is an opening for the two different paradigms, Western biomedical and Aboriginal and Torres Strait Islander healing, to sit beside one another in burns care. Burns care at the interface of knowledges could be supported by healthcare professional with skills to understand how these paradigms influence their practice and the resources and explicit guidance to inform such translation into care.

To support improvements in healthcare for Aboriginal and Torres Strait Islander peoples, the Australian Commission on Safety and Quality in Health Care (ACSCHC) has defined six actions that specifically aim to meet the needs of Aboriginal and Torres Strait Islander peoples in the new standards (NSQHS 2017). They are required to be met by tertiary healthcare services from 2019 onwards and include: 1. working in partnership; 2. addressing specific health needs; 3. monitoring improvement strategies; 4. improving the cultural awareness and cultural competency of the workforce; 5. demonstrating a welcoming environment; and 6. improving identification rates. The development of such assessed standards for care creates accountability for the delivery of culturally competent healthcare. Consideration of how the three main findings from this study - dominant use of biomedical paradigm and limited consideration of equity and reflexivity, along with interfacing Western biomedical knowledge and Aboriginal and Torres Strait Islander knowledge - may inform the actualisation of the six elements in the NSQHS standards for translation into care will be done throughout this discussion.

Interfacing knowledges in burns care

The ways of knowing, being and doing for Aboriginal and Torres Strait Islander peoples are different to those of non-Indigenous peoples (Martin 2003). Helen Milroy describes the holistic health model integral to Aboriginal and Torres Strait Islander peoples as a multi-dimensional concept that includes *physical*, *psychological*, *social health and wellbeing*, *spirituality* and *cultural integrity* (Milroy 2006). This model has previously been used to critique and explore the impact on health of government policy (Australian Indigenous Doctors' Association 2010). The dominant use of the Western biomedical paradigm in burns care for Aboriginal and Torres Strait Islander children in Australia is limited in its ability to ensure care addresses such critical constructs.

Data from this study showed that in Australia, the *physical* aspects of burns care are predominantly informed by scientific evidence which guides high quality medical and surgical components of burns care (Government of Western Australia 2009, ACI 2011, Kim, Martin & Holland 2012, Government of South Australia 2014). These components of care rely heavily on this evidence and its use has led to improved outcomes following a burns injury, including such things as reduced rates of mortality and improved morbidity (WHO 2018). While these outcomes have been realised across populations (WHO 2018), the use of only a single body of knowledge to inform care limits overall quality for those people whose constructs of health and healing go beyond a purely biomedical model as is the case here (Mackean, Laverty, Best & Fredericks). Furthermore, *physical* health for Aboriginal and Torres Strait Islander people relates strongly with a connection to Country (Milory 2006). While telehealth aims to address this component of health and connection to Country, especially for those geographically dislocated for care, the cultural competency of such a modality is unclear (Fraser et al. 2017) and multidisciplinary burns teams in Australia generally do not consider it.

Reccomendation 1: Acknowledge and demonstrate the value of Aboriginal and Torres Strait Islander people's knowledge by integrating cultural considerations into telehealth.

Psychological care for a burns injured person or family is care that deals with psychological issues that may arise from trauma (Government of Western Australia 2009, ACI 2011, Government of South Australia 2014). Sources of trauma for Aboriginal and Torres Strait Islander peoples include those reflected in trans-generational trauma and cumulative trauma (Milory 2006). The psychological components of health in mainstream burns care are supported through multidisciplinary teams (Kim, Martin & Holland 2012) and engagement with relevant professions, however falls short in adequately addressing trans-generational trauma (Dudgeon, Milroy & Walker 2014). Data from burns teams members showed psychological care in burns is not mandatory in the multidisciplinary team environment, and descriptions of care by healthcare participants did not include that of the provision of care for trans-generational trauma or cumulative trauma. However, the ACI model of care for burns does state that psychological care is mandatory.

Data identified engagement of social workers in burns care and their use of profession specific frameworks for care that address a families' capacity to succeed in the tertiary healthcare environment were important. Social worker also supported families to meet the requirements of caring for their child. The *social health and wellbeing* construct in Milroy's holistic health model relates to the impacts of past policies and practices on Aboriginal and Torres Strait Islander peoples (Milory 2006). Where an experience of dislocation of families and communities has led to disadvantage and subsequent poor living conditions (Milory 2006). The social work profession and its involvement in multidisciplinary burns care is well placed to support families with social health and wellbeing.

Reccomendation 2: Mandatory inclusion of social workers in the provision of burns care to attend to the psychological and social care of families.

Findings showed burns care in Australia is limited in its delivery of both spiritual and cultural care for Aboriginal and Torres Strait Islander people. *Spirituality* for Aboriginal and Torres Strait Islander peoples is shown in their understanding of the creation and connectiveness of life (Milory 2006). A denial of the importance of such constructs as contributing to balance and good health limits the capacity of Aboriginal and Torres Strait Islander peoples to experience best health (Milory 2006, Laverty, McDermott & Calma 2017, Mackean 2009). Similarly, the dismissal of *cultural integrity* including Aboriginal and Torres Strait Islander people's lore and law, languages, ceremony, kinship and approaches to health and healing (Milory 2006), is central to an experience of poor health and healing (Laverty, McDermott & Calma 2017, Mackean 2009, Best & Fredericks 2018). However, where multidisciplinary burns team members' understood the requirement to do things differently, along with an acceptance of the necessity of basing care on consumer needs as vital in the provision of quality care, best quality care was more likely to be realised.

The provision of care that is not purely embedded in the scientific paradigm partly informs meeting the NHSQHC element of 'addressing specific health needs' (ACSCHC 2017), and as such, contributes to equitable burns care. In order to facilitate and further support burns teams in the provision of such care, healthcare providers need to be given support and the tools to do things differently; to enact equitable practice. The theory of cultural safety and associated principle is well positioned to support recommendations for how to actualise the interfacing of knowleges in burns care.

Cultural safety in burns care

Cultural safety has been shown to be an experience of care (Laverty, McDermont & Calma 2017, Ramsden 2002, Taylor & Guerin 2014) and a theory relative to inform research and healthcare for Aboriginal and Torres Strait Islander peoples (Fraser et al. 2018, Mackean et al. 2019). The five principles of cultural safety include *regardful care, power differentials*, *reflexivity*, *decolonisation* and *dialogue* (Ramsden 2002, Taylor & Guerin 2014, Best & Fredericks 2018). This research has engaged the theory of cultural safety to critique burns injury models of care to assess their ability to address each of the five principles. The models were found to not address all principles (Fraser et al. 2018). The theory was also used for further synthesis of family data in the testing of the patient journey mapping tool. It proved useful to assess risk in terms the families' experience of culturally safe care. I now present further considerations of how these principles in terms of the main findings regarding the structure and delivery of burns care, leads to an experience of culturally safe care for Aboriginal and Torres Strait Islander children and families.

Our analysis identified members of multidisciplinary burns teams are only sometimes recognising the need for different care for Aboriginal and Torres Strait Islander children and families.

Furthermore, there was evidence of confusion about the necessity to provide different care based on differing needs, thus limiting the capacity of burns care to be realised as best quality for this population. Addressing the needs of consumers in healthcare ensures all aspects of quality are being addressed and met (ACSQHC 2010). Furthermore, meeting people's needs is linked to *regardful care*, which is provision of care that is regardful of culture and challenges the status quo of providing care that is regardless of culture (Ramsden 2002, Taylor & Guerin 2014, Best & Fredericks 2018). The provision of such care is linked to addressing equity in access to healthcare (Scrimgeour & Scrimgeour 2008) and equity in the provision of healthcare sometimes means it is necessary to do things differently for different populations. When the provision of healthcare in Australia is predominantly framed in a biomedical model (as has been shown to be the case for burns care), different care is necessary for any population who prescribe to a model other than this (Taylor & Guerin 2014), or whose constructs of health and healing require consideration of factors not inherent in the biomedical model (Milory 2006, Mackean 2009). This means equity in healthcare is not being fully realised for Aboriginal and Torres Strait Islander children and families accessing paediatric burns care in Australia.

We found that hierarchal team structures led by medical personnel, impede the ability of burns care to be truly multidisciplinary. This is despite existing best practice evidence for multidisciplinary burns care (D'cruz, Martin & Holland 2013). As a result, power imbalances develop, and the dominant and normative approach to care prevails as is the case identified in this study. Minimising *power differentials* in healthcare supports the role of maintaining dignity for Aboriginal and Torres Strait Islander peoples (msden 2002, Taylor & Guerin 2014, Best & Fredericks 2018). Data identified Aboriginal/Indigenous liaison officers (A/ILOs), who understand and address cultural care and consider the importance of connection to Country and family (Milory 2006) are only sometimes included in the multidisciplinary burns team. This is because, more often than not, these aspects of care are not systematically or consistently considered part of the normative approach to care in Australia (Best & Fredericks 2018). So, while A/ILOs are well placed to provide or ensure the provision of this type of care (Katzenellenbogen, Miller, Somerford et al. 2015), systematic inclusion in multidisciplinary burns team is limited, therefore limiting the quality of multidisciplinary burns care. Increased realisation of the vital contribution of A/ILOs in healthcare, along with corresponding resources may improve the provision of *regardful care* and *decolonisation* and supporting a more balanced *power differential*.

A/ILOs are critical to the actualisation of all six NHSQHC elements listed above (ACSCHC 2017). This research has demonstrated there is opportunity for interfacing Aboriginal and Torres Strait Islander people's knowledge with biomedical knowledge in research as is the case in healthcare. There is opportunity then for the systematic inclusion of A/ILO in multidisciplinary burns teams, especially for inclusion in case conferences where individual cases are discussed and care is planned. This example would partly inform meeting the NHSQHC element of 'working in partnership' (ACSCHC 2017). Inclusion of the A/ILO would help to ensure Aboriginal and Torres Strait Islander people's ways of knowing, being and doing are considered in conjunction with the dominant biomedical focus.

Reccomendation 3: Systematic inclusion of A/ILO in burns care for Aboriginal and Torres Strait Islander children and families, including being written in the documents that inform care with explicit guidance on engagement and contribution to care.

Our analysis identified burns teams do partly address the cultural safety principle of *dialogue*. *Dialogue* is about working in partnership, building relationship and being respectful (Ramsden 2002, Taylor & Guerin 2014, Best & Fredericks 2018). Our analysis identified that burns team members engage in such care with children and families, often with the aim of determining their level of understanding. This shows some *reflexivity* in practice, however data in this study mostly showed little to no evidence of engagement in *reflexivity* in terms of engaging in a decolonising practice by members of the multidisciplinary burns team.

There is evidence about the use of *reflexivity* in research methodology (Wilson 2014, Mackean et al. 2019), however when discussed in relation to healthcare practice, it can be referred to as critical reflective practice. The theory of reflexivity used in the context of this research about healthcare for Aboriginal and Torres Strait Islander children and families, encompasses a decolonising agenda. There is little evaluation research evidence in the literature about the use of *reflexivity* in healthcare practice and its resultant outcomes, nor does it explain how to do it. Paradies et al (2013) and Kowal et al (2013) write about reflexive antiracism as it relates to diversity training, of which could be applied to other settings like healthcare. Engaging in critical *reflexivity* has been shown to provide a space for people to assess their own culture and biases, in order to enhance understanding of their own and other's culture (Wilson 2014). Engagement in *reflexivity* in the research setting has shown to provide opportunities to enhance knowledge and alter practice in order for experiences to be perceived as culturally safe (Wilson 2014). Therefore, *reflexivity* in healthcare is about reflecting on practice with mutual respect for different ways of knowing being and doing. It is evident here there is capacity for reflexivity to be used to enhance quality of burns care for Aboriginal and Torres Strait Islander children and families. In this setting, reflexivity is linked to *decolonisation* whereby there is acknowledgment of the key role of a colonising history in contemporary health outcomes for Aboriginal and Torres Strait Islander peoples. Engaging in reflexivity may be through facilitated case studies with incorporation of Aboriginal and Torres Strait Islander people's knowledge whereby healthcare providers are able to reflect on care and identify areas for improvement and act on these accordingly. Engagement in reflexivity by healthcare practitioners will inform meeting the NHSQHC elements of 'improving the cultural awareness and cultural competency of the workforce', which also may contribute to 'improve(ing) identification rates' (ACSCHC 2017). Furthermore, engagement in reflexivity is one option to enhance understanding and further support acceptance of the need to do things differently (Wilson 2014).

Reccomendation 4: Develop a clear body of knowledge about translation of reflexivity into practice so that multidisciplinary burns teams can systematically incorporate reflexivity into practice.

The value of interface research methodology

Key components in the first section of this thesis demonstrate Western knowledges are not congruent with Aboriginal and Torres Strait Islander peoples' knowledges, especially as they relate to health and healing in Australia. Western biomedical knowledge is built upon scientific evidence, that leads to care that is compartmentalised (Taylor & Guerin 2014, p. 112). This contradicts the holistic health construct of Indigenous peoples (Australian Indigenous Doctors' Association 2010). This domination of knowledges is the driving force behind the processes of colonisation and its perpetuation in the current Australian health system (Commonwealth of Australia 1997, Moreton-Robinson & Walter 2009). Both in terms of power and race, this denial of any relevance of Indigenous knowledges and inability to work together is a significant component of colonisation (Commonwealth of Australian 1997, Moreton-Robinson & Walter 2009). In Australia, the process and perpetuation of colonisation, with the belief that white ways are more important than Indigenous ways as a driving force, contributes to the marginalization and disempowerment of Aboriginal and Torres Strait Islander peoples (Commonwealth of Australian 1997, Moreton-Robinson & Walter 2009). It is this erroneous superior ideology that creates the marginalised, broken Aboriginal and Torres Strait Islander family environments seen in Australia today (Dudgeon, Milroy & Walker 2014). These environments lead to, amongst many things, an increase in risk and vulnerability (Milroy 2008) that is evident in numerous domains and can be seen in the health outcome inequities experienced by Aboriginal and Torres Strait Islander children (AIHW 2011b). One such example being that Aboriginal and Torres Strait Islander experience burns injury at disproportionally higher rates than non-Indigenous children (AIHW 2011b, Möller et al. 2017). The use of interface research methodology led to the identification of the conflict between world views and the process of colonisation as the root cause of inequities as a whole which has subsequently been found to be manifest in burns care in Australia.

The value of interface research methodology has been realised to address health inequities and the complex care requirements when an Aboriginal and Torres Strait Islander child is severely burnt and subsequently requires care in a Western biomedical system. Other methodologies would not enable the understandings that research at the interface has facilitated, especially in the relation to nuances about healthcare providers' implicit biases. The patient journey mapping tool is a method of working at the interface and highlights how knowledge's can constructively work together.

Reccomendation 5: Interface Western biomedical and Aboriginal and Torres Strait Islander knowledges in a model of care such that it results in a carefully and deliberately created model that ensures all concepts of health and healing are considered and gives explicit guidance for the provision of such care.

Strengths and limitations of the research

This is the first study to investigate burns care from the perspective of multidisciplinary burns teams across Australia. The use of interface research methodology has ensured the research processes and outcomes are relative to Aboriginal and Torres Strait Islander children and families. This study investigated what informs burns care for Aboriginal and Torres Strait Islander children and families, along with an exploration of the constructs of equity and equality in burns care and an assessment of quality and cultural safety in burns care. The ecological framework provided a systematic way of exploring how the various factors involved in multidisciplinary burns care for Aboriginal and Torres Strait Islander children and families interact across multiple levels of the healthcare system and relate to and influence each other.

Drawing on recruitment across multidisciplinary burns care teams increased the likelihood that all professions involved in burns care for Aboriginal and Torres Strait Islander children and families were represented. However, not all of the people employed and working within burns teams were interviewed. Nonetheless, the collection of a large amount of qualitative data from on-site face-to-face interviews with many burns team members enabled everyday practices to be comprehensively explored.

Data collection with clinicians was enhanced by me, the principal researcher being a registered nurse with a thorough understanding of health systems and processes. However, as the research was about health and healing for Aboriginal and Torres Strait Islander children, the process of decolonisation through reflexivity was imperative, because I am a non-Indigenous healthcare professional primarily educated within a biomedical standpoint. My non-Indigenous standpoint was also specifically addressed through Aboriginal oversight and involvement in research process and data analysis. In addition, the majority of data collected were from burns team members and did not include the viewpoints of families receiving burns care. This was balanced to some extent by the family data collected for the testing of the patient journey mapping tool. As a result, the ability to fully understand how children and families feel about the burns care they receive was a limitation of the study. These data are being collected by other members of the research team involved in the larger NHMRC funded study.

Concluding statement

As the first focused study on burns care for Aboriginal and Torres Strait Islander children and families with a large sample of multidisciplinary burns team members, this thesis provides the best available information to date about burns care as it relates to the provision of care that prioritises consideration of the health and healing constructs of Aboriginal and Torres Strait Islander peoples. Thus, this work constitutes a significant advance in current knowledge in this under-researched space.

This thesis provides a detailed source of information about burns care for Aboriginal and Torres Strait Islander children and families. The findings suggest the need for improved awareness by healthcare practitioners who work with and provide care to Aboriginal and Torres Strait Islander children and families. Further research and attention needs to be directed towards the stories of Aboriginal and Torres Strait Islander children and families. It is hoped that these findings will help inform healthcare and future evaluation research and ultimately prompt action to improve burns care for many Aboriginal and Torres Strait Islander children and families and other Australians who are required to access healthcare for burns care.

I found that burns care in Australia for Aboriginal and Torres Strait Islander children and families is predominantly delivered by clinicians who understand the need for equitable care. However, the ability to provide equitable care is limited as a result of the structure of the healthcare system and the healthcare service within which they work. When there is no consideration of the need for different burns care for Aboriginal and Torres Strait Islander children and families, the full potential of its capacity to be best quality burns care for and experienced as culturally safe by Aboriginal and Torres Strait Islander children and families is limited.

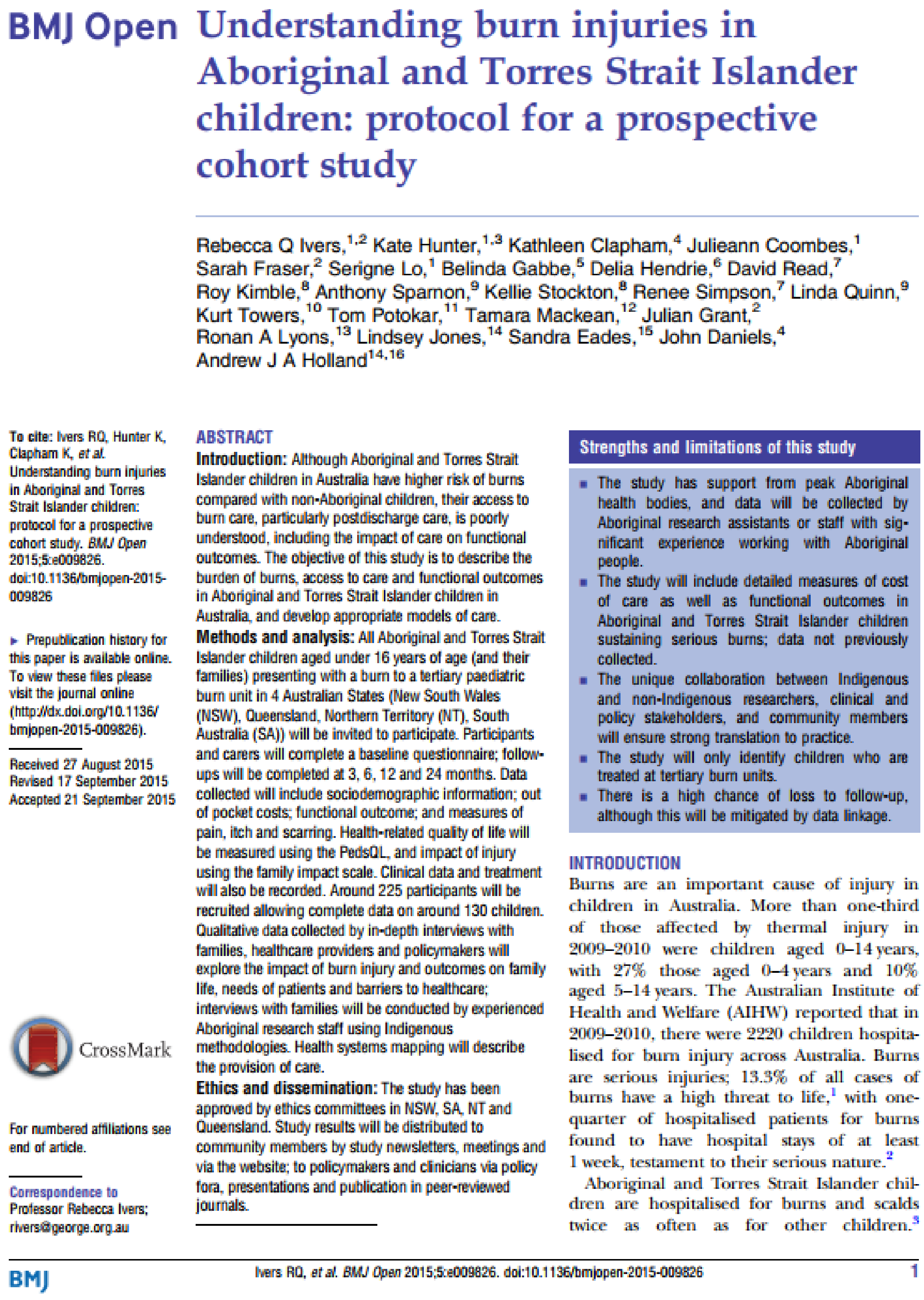
We found an intricate web of constructs that inform health systems and services and healthcare professionals in providing burns care to Aboriginal and Torres Strait Islander children and families. The use of an ecological framework provided a cohesive way to show how overarching healthcare context, created at national and jurisdictional levels, informs care at the health service and burn unit level, and also how those parameters and ideas influence care at a team and individual level. This analysis facilitated an ability to situate healthcare delivery at the individual level in the broader health system context. The values and beliefs embedded in the broader health system, in which the health service team and individuals are located, are heavily influenced by a positivist paradigm. There was a need to understand this interrelatedness across all levels of the Australian healthcare system and across the various factors informing burns care as it relates to Aboriginal and Torres Strait Islander children and families. This is important as factors informing care are not separate from each other; rather they are interdependent of one another. As a result, there are clear opportunities to improve healthcare for Aboriginal and Torres Strait Islander children and families in Australia; especially as it relates to burns care. Burns care, currently structured in a predominantly biomedical paradigm, with colonial ideologies informing service structure and clinician beliefs, can be improved by the careful consideration, inclusion and uptake of evidence linked to better care for Aboriginal and Torres Strait Islander children and families.

The difference between a clinicians' intentions and resultant care for Aboriginal and Torres Strait Islander children and families may be due to a lack of adequate resourcing as well as a lack of Aboriginal and Torres Strait Islander knowledge input. While many clinicians want to provide a better and more appropriate burns care for Aboriginal and Torres Strait Islander children and families, there is tension between the competing demands for achieving clinical quality indicators, organisational efficiencies and decolonising a system entrenched in colonial ideologies.

Burns care for Aboriginal and Torres Strait Islander children and families in Australia is still predominantly informed by non-Indigenous concepts of health, healing and care delivery. The disjuncture between Western biomedical and Indigenous healthcare paradigms negatively impacts the delivery of care for Aboriginal and Torres Strait Islander children. Burns is an important but not isolated example. The current power imbalance in favour of the scientific approaches to burns care extenuates this negativity, and constructive action is required to address this inequity. Constructive action includes the development of a new model of care for burns in Australia. For the new model of care to address the inequity, it needs to be developed in line with the NHMRC guidelines (NHMRC 2011) and within a framework that applies the theories of cultural safety (Ramsden 2002) and Milroy's holistic health model (Milroy 2006). This would mean applying an interface approach and the inclusion of Aboriginal and Torres Strait Islander people's knowledge in a model of care and consequent delivery of that care.

SECTION D: APPENDICES AND REFERENCES

Appendix 1 - Understanding burn injuries in Aboriginal and Torres Strait Islander children: protocol for a prospective cohort study



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

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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]

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 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

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 Records Data‡	POSAS† Hospital Medical Records Data‡	POSAS† Hospital Medical Records Data‡	POSAS† 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 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 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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Appendix 2 - Rehabilitation practices for burn survivors in low and middle income countries: A literature review

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Review

Rehabilitation practices for burn survivors in low and middle income countries: A literature review

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ABSTRACT

Objective: To systematically review the delivery and effectiveness of rehabilitation for burn survivors in low and middle income countries (LMIC).

Methods: We systematically searched the literature through 11 electronic databases and the reference lists of relevant studies. Studies were suitable for inclusion if they were primary research with a focus on burns rehabilitation in LMIC settings describing either service delivery or treatment effectiveness. No time, design or other limitations were applied, except English language.

Results: Of 226 studies identified, 17 were included in the final review, including 7 from India. The results were summarised in a narrative synthesis as the studies had substantial heterogeneity and small sample sizes, with many relying on retrospective data from non-representative samples with no control groups. Most studies (12) described service delivery and 5 examined the effectiveness of different types of rehabilitation. Multiple studies stressed the need for rehabilitation and multidisciplinary teams for burns management.

Conclusions: The published research on burns rehabilitation is very limited and little is known about current practices in LMIC settings. In order to inform policy and service delivery, the effectiveness, feasibility and sustainability of current services needs to be investigated.

Contents

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1. Introduction

Burns contribute significantly to the global burden of death and disability: in 2015, injuries caused through exposure to fire, heat or hot substances led to the loss of over 12 million disability-adjusted life-years (DALYs) worldwide, and were attributed to over 180,000 deaths [1]. The World Health Organisation (WHO) describes burns as the 'forgotten global public health crisis' [2]. Burns have not received sufficient attention in global or national policy initiatives — they did not fit under any of the Millennium Development Goals, and are not directly mentioned in the subsequent Sustainable Developmental Goals [3,4].

The largest burden of burns are in low- and middle-income countries (LMICs), where prevention programs are inadequate or absent and healthcare resources are stretched, with limited acute care or rehabilitation services available for burns victims [5]. Over half of all burns-related deaths in the world occur in the South East Asia region, where India bears the largest burden with over a million people moderately or severely burnt every year [6]. Further, 60% of these deaths occur in women, mostly aged between 15 and 34 years [7]. Young females have been consistently reported across multiple hospital-based studies as a high risk group with the average male:female ratio of fire-related deaths of 1:3, the only injury with over-representation of women [7]. Prevention efforts face challenges particularly in the context of intent of the injury amongst women, with family violence and self-immolation common contributors to burn injury [7].

Few burn victims in LMICs receive appropriate first aid or immediate acute care, which can lead to further complications. Lack of co-ordinated management of a burn injury may result in complex psychological problems such as anxiety, depression and post-traumatic stress disorder, often leading to fatalistic attitudes and the belief by patients and carers that little or nothing can be done for pain management and to relieve suffering [8]. As a result, burn survivors become emotionally overwhelmed and typically withdraw [9]. Unfortunately, this lack of activity exacerbates secondary problems, such as contractures, thereby heightening the survivor's disability [10,11]. The distribution of burn morbidity also varies across settings and the prevalence of moderate and severe disability due to unintentional injuries in people under 60 years of age is 35.4 million in LMIC settings; 12.5 times higher than in high income countries (HIC) [12]. Populations in LMICs have a higher exposure to risks associated with burns, such as cooking fires and fuels [13].

Reported costs for burns treatment in India are comparatively high when compared to other LMICs. A tertiary hospital setting in India reports an average per patient cost of USD885 for burns treatment [14], while comparable work from Vietnam reports an out-of-pocket cost of USD427 per burns case [15]. Rehabilitation is defined as strategies involved in functional recovery and community reintegration from disability [16]. Coordinated rehabilitation with access to a multidisciplinary team minimises adverse effects of burn injury by preventing contracture development and the impact of scarring, and by maximising functional ability, psychological wellbeing and social integration [17]. Burns injury care in LMICs face several challenges, primarily because of limited resources, the absence of adequately trained health personnel, a lack of facilities equipped with essential resources, the lack of guidelines for best practice, the concentration of services in urban areas, as well as an array of access barriers for patients [18,19]. Ideally, burns rehabilitation should integrate the physical, psychological and social aspects of care as it is common for patients to experience difficulties in one or all of these areas following a burn injury. It is not known what burns rehabilitation services are available, accessible or most effective for low resource settings. Appropriate burns care that follows evidence-based guidelines to ensure the best outcomes for patients is unlikely to be achievable and sustainable within the overworked, under-resourced health care systems of LMICs, unless novel low cost models of care are developed. In order to inform development of such models of care, there is a need to understand the current practices, resources and effectiveness of rehabilitation in hospitals, homes and communities in LMICs. We carried out a systematic review of available literature to appraise the care practices and effectiveness of burn related rehabilitation in LMICs.

2. Methods

2.1. *Search strategy*

A systematic search of published literature was completed in 11 electronic databases: MEDLINE, Scopus, CINAHL, Web of Science, Web of Knowledge, SafetyLit, Cochrane Library database, Centre for Reviews in Health Systems and International Development, Global Health Library, International

Table 1 – Search terms used to identify relevant studies.

Population	
1	Developing countr* or LMIC
2	Communit* or home*
Exposure	
3	Fire* or burn* or flame*
4	Rehab* or treatment
Outcomes	
5	Injur* or damage* or trauma* or wound*
6	Death or mortality or fatal* or die* or decease* or morbidity
Combining search	
	1 and 2 and 3 and 4 and (5 or 6)

* includes derived forms of each search term.

Online Resource Centre on Disability and Inclusion, and India Med. Search terms included the following strings and relevant medical subject headings (MeSH terms): "burn", "rehabilitation" and "developing countries", and "injury", "community/home based" "rehabilitation" and "developing countries" (Table 1). Individual names of low and middle-income countries were also included. Relevant internet sources including Google Scholar were also searched to identify other potentially relevant articles.

2.2. *Inclusion criteria, data extraction and quality appraisal*

Studies were suitable for inclusion if they were primary research from LMIC settings, describing service delivery or evaluating the effectiveness of burns rehabilitation services. No publication date period or other limitations were applied, except English language. LMICs were defined as those published by the Australian Governments Department of Foreign Affairs in 2015 [20].

Study selection and data abstraction were carried out using a standard data abstraction form (Table 2) by one author (CL). The study selection process is summarised in a flow diagram (Fig. 1).

3. Results

Initial searches identified a total of 333 research papers, from which 59 were identified as potentially relevant based on the screening of titles and abstracts. Excluded articles were either duplicates (105) or did not fulfil inclusion criteria (167). From the 59 articles selected for full review, a further 35 were excluded because they did not fulfil the inclusion criteria. The remaining 17 studies are summarised in Table 2. Characteristics of the study, including limitations, are presented. The process for identifying studies is outlined in Fig. 1.

The 17 studies retained for inclusion reported on various aspects of patient rehabilitation following burn injury in LMICs (Table 2). Due to the substantial heterogeneity between

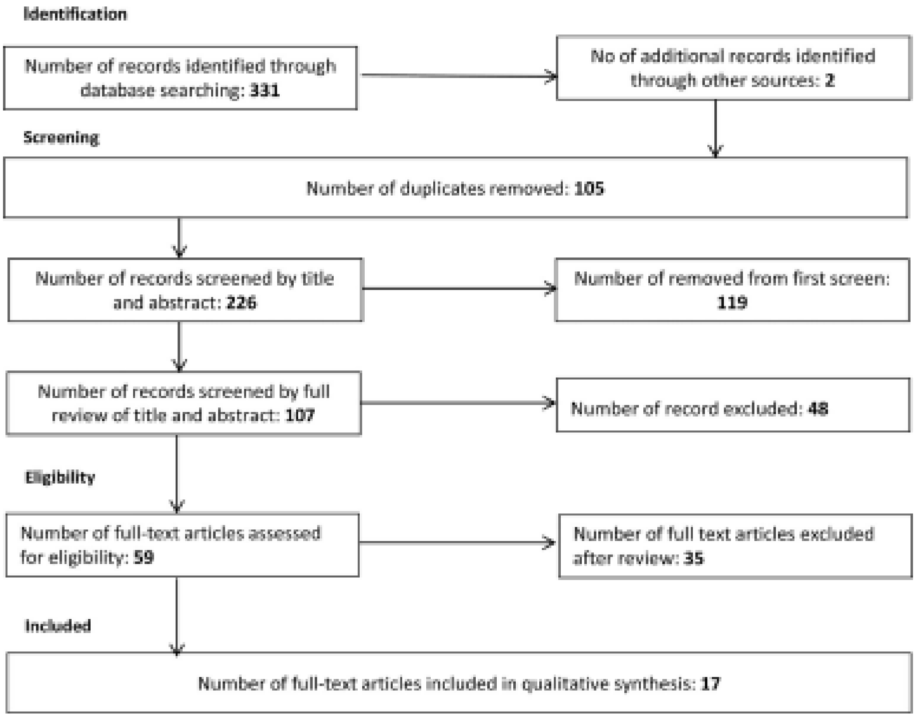

Fig. 1 – PRISMA flow diagram of the number of records identified, included and excluded in the study.

Table 2 – Standardised data extraction table summarising studies included in the review.

Study	Country	Aim/focus	Study type	Participants	Intervention	Outcome	Limitations	Comment
Burns due to acid assaults in Sri Lanka [21].	Sri Lanka	To describe the epidemiology, mechanism, complications, management challenges, and related psychosocial factors associated with acid assaults.	Retrospective, descriptive A retrospective review of patient records from a Burns and Reconstructive Surgical Unit over an 18 month period. Evaluated variables included, amongst other things, compliance with rehabilitation.	n = 46	Rehabilitation intervention not detailed. Participants rehabilitative team included occupational and physio therapists for mobilizing and splinting; psychologists and counsellors.	Attendance to the follow-up rehabilitation clinic was observed only in 18 (39%) patients.	Retrospective data. Small sample size.	Patients constitute cohort of patients with worst compliance in rehabilitation process because they do not attend the follow-up clinic regularly. Reasons not clear, but may be the perceived persisting threat of a recurrent incident, or scarring and altered appearance imply a stigma, preventing leaving home.
A comparison between two burn rehabilitation protocols [35].	Iran	Compare two burn rehabilitation protocols.	Comparison Burn patients were randomly assigned to 2 different physio treatment groups: Group 1 = conventional physiotherapy Group 2 = burns rehabilitation therapy	n = 30	Routine burn physiotherapy compared to burn rehabilitation treatment protocol with higher frequency, longer and early physiotherapist intervention. Intervention also included specific rehabilitation for burns care such as use of splinting, ankle pump exercises, emphasis on stretching exercises, carer education, and protection of skin grafts and scar management.	Significant difference ($p < 0.01$) in burn contractures between two groups. BRT group, 6% had burn contractures, with 73% routine rehabilitation treatment. No difference between groups in thrombosis prevention and duration of stay at the hospital.	Small sample size.	Emphasis on need of quality of physiotherapy better recovery outcomes in burns patients.
Effects of a skin rehabilitation nursing program on skin status, depression, and burn-specific health in burn survivors [36].	Korea	Identify the effects of a skin rehabilitation nursing program (SRNP) on skin status, depression, and burn-specific health in Korean burn survivors.	Pre/post design Participants with burn injuries on forearms and/or hands trialled a burn rehabilitation program for a 3 month period.	n = 26	The SRNP group of 13 burn survivors received 36 (each) massage therapy sessions 30 min three times a week for 3 months and caregivers moisturized the scars daily in addition to constant reminders and an information booklet from the research team; compared to a control group of 13 burn survivors receiving usual care.	The SRNP group showed no significant changes in the burn scar, subjective skin status, depression, or burn-specific health, but had reduced burn scar depth.	Small sample size. Short intervention time frame. Non-equivalent control group.	Suggests education provided to home caregivers could improve health outcomes. Future studies with a larger sample are needed.
Paediatric rehabilitation in a developing country — India in relation to aetiology, consequences and outcome in a group of 459 burnt children [22,46].	India	Relationship between age, aetiology, percentage body surface area burnt, social and economic status of individual and necessity for rehabilitation.	Retrospective, descriptive A retrospective review of patient records from a paediatric burns facility over a 10 year period.	n = 459 Case records of 459 children who were admitted during 10 year period (1993–2002)	Rehabilitation intervention not clear. Rehabilitation in this context includes functional, cosmetic and psychosocial aspects, however was not explicitly stated as the intervention.	A total of 13.7% of burnt children needed functional rehabilitation; children from poorer socioeconomic strata of society are not able to get comprehensive rehabilitation due to the financial constraints; patients came from peripheral areas of the state. Higher education results in rehabilitation; psychosocial rehabilitation was not reported as a need in the younger paediatric cohort.	The need for rehabilitation was assessed, however the tools used are not well established.	Authors discuss need for a support to carers and the cost of rehabilitation is prohibitive.
A survey on the current status of burn rehabilitation services in China [23].	China	Determine current status of burn rehabilitation services in China.	Quantitative, cross-sectional Survey Questions investigated admissions and staffing of burn centres; availability of rehabilitation services; number and educational background of specialised rehabilitation personnel; difficulties leading to the lag of the burn rehabilitation services	n = 39 (44.8% of 87) burn centres contacted via email and phone	Pressure garment (100%), splinting (84.2%) and physical therapy (81.6%) are reported to be the most common rehabilitation services provided at the centres.	More than 70% centres began their rehabilitation therapy 1–2 weeks after burn injury. Acute stage rehabilitation is done using splints, range of motion exercise and ambulation.	<50% representation of burn centres. Those who did not respond may indicate their rehabilitation services have not been started.	Suggests: provide rehabilitation education programmes for staff and community at large; set up standard guidelines for clinical rehabilitation therapy; build interdisciplinary burn team; increase staffing and funding; increase research on burns for problem identification and suggesting solutions; offering insurance to burns survivors.
Telemedicine utilization to support the management of the burns treatment involving patient pathways in both developed and developing countries: a case study [27].	Taiwan	Report on utilization of telemedicine to support the management of burns and improve doctor-patient relationship.	Case study Documentation of patients admitted to hospital with severe burn injuries. Details of injury, treatment provided and health outcomes 10 months following treatment provided.	n = 2 Both cases sent to local hospital and treated by wound dressing without surgical intervention or rehabilitation.	Clinical evaluation by telemedicine to determine the range of motion of the joints and provide rehabilitation.	Subjective reporting that telemedicine improved care management throughout entire patient pathway, diagnostic, follow-ups, rehabilitation.	No objective outcome measures were used to report the outcomes.	Perceived benefits of telemedicine: Better support for understanding severity of burn injury and to evaluate limb movements. Improved support for establishing and maintaining the doctor-patient relationship. Improved continuing medical education for physicians located at the hospital in the developing country.

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Table 2 (continued)

Study	Country	Aim/focus	Study type	Participants	Intervention	Outcome	Limitations	Comment
A quantitative, cross-sectional study of depression and self-esteem in teenage and young adult burn victims in rehabilitation [24].	Brazil	Assess presence of depression and level of self-esteem in teenage and young adult burn victims receiving follow-up (physical and psychological rehabilitation) care for their injuries. Determine whether the location of the burn (hand or head) or current work condition is a factor in psychological condition.	Quantitative, cross-sectional Three instruments for assessing depression/low self-esteem administered to teenagers/young adults undergoing burn rehabilitation.	n=63	Participants received physical and psychological rehabilitation for an average of 124.74 months (SD 63.67) from a multidisciplinary team, tested using Beck's Depression Inventory (BDI) & Rosenburg's Self Esteem Scale (RSE).	Scores for depression and body image in the study participants were reported to be better in those who were able to go back to school or work.	Small sample size. No comparison group. Routinely collected data has limitation in terms of quality and completeness.	Comparison between teenagers and young adults with and without a history of burn injury would be useful.
Adjustable aesthetic aeroplane splint for axillary burn contractures [31].	India	Describe rehabilitation equipment, namely, an aeroplane splint that is modified to make it more appealing, and improve compliance and acceptance.	Descriptive review An outline of the aeroplane splint and its use in burn injury rehabilitation.	N/A since the modifications to the orthosis are described. No patient data.	Managing axillary burns used in rehabilitation with a new model of the Aeroplane Splint with innovative changes (cost effective and lighter) for use in community.	N/A	Descriptive – developing new splint model.	A barrier to environmental accessibility is multiple permanent structures; narrow thoroughfares, entry/exit sites of public transports, narrow aisles, and like, which is a challenge to rehabilitation professionals while prescribing large splints.
What is missed in self-immolated patients' care?: a grounded theory study [30,47]	Iran	To explore rehabilitation care process in patients who commit self-immolation, using grounded theory.	Qualitative, descriptive Semi-structured interviews, diaries and observations used for data collection.	5observations, 8 diaries and 28 interviews from 10 participants (2 M and 8 F)	Rehabilitation intervention not clear.	Rehab care provided by healthcare providers is not professional and purposeful for self-immolated patients. There is unintegrated care of the survivors. While patients, family and rehabilitative team tried to help the patient with self-management, there were no combined efforts instead of co-ordinated strategies.	Unable to assess for significance of results.	Suggests: approach of the rehabilitative team toward self-immolated patients should be more sympathetic. Inter-relationships between rehabilitative team, family and community is crucial and needs to be established. Caregiver education is important.
Embracing survival: a grounded theory study of parenting children who have sustained burns [29].	India	Explore and discover the process of parenting children in India with burn injury at home and develop a conceptual model to inform interventions.	Qualitative, descriptive Semi-structured interviews (25), diaries and observations used for data collection.	n=22 22 family members of 12 burn-injured children	Parents provided rehabilitative care at home to burn injured child.	Parent's demonstrated perseverance in meeting burn-injured child's needs at home. Burn-injured child was not seen as a burden.	Data collected only from family members and not from burns survivors and health care providers; small sample size.	Suggests: health care providers need to be sensitive about parents' needs. Use of genograms and eco-maps to identify those who can help the parents with home rehabilitation.
Burn rehabilitation: a challenge, our effort [26].	India	Paper discusses certain examples of successful rehabilitation strategies for burns.	Case study Description of protocols for burns admissions to one medical centre. 2 case studies included to illustrate protocol function.	n=2	Multidisciplinary approach: chest physiotherapy, splinting, range-of-motion exercises, positioning, psychological therapy, pressure garments, massage, activity-of-daily living training, surgical release of contractures	Case 1: complete recovery from burns injury; vocational rehabilitation helped the survivor to get back to education and work; social re-integration Case 2: return to home with better physical and psychological status	Descriptive subjective outcomes reported.	Suggests: inclusion of leisure into burns rehabilitation using multi-disciplinary approach. Holistic approach to burns management. Social group activities for networking. Formation of peer support group for burns survivors.
Rehabilitation and social adjustment of people with burns in society [25].	Pakistan	To explore the relationship between social adjustment of people with burns and their psychosocial rehabilitation.	Quantitative, cross-sectional Patients from a Burn Treatment Centre ranked their experiences with social adjustment following a burn injury.	n=186	Documentation of psychosocial rehabilitation. Assessment using validated Likert scale.	Associations between psychosocial rehabilitation and feeling shame in the society, burns as a hurdle to contact other members of the society, insult from society, loss of social network and societal social support for burns survivors were significant (at $p < 0.05$).	Limited to one site.	Suggests: proper awareness about the gravity of the problem, embodied in the cultural flaws, associated to these people with burns in the light of religion and moral obligations of the society. Cash's model of body image proved of little help to explain the phenomenon of burns.
The effect of burn rehabilitation massage therapy on hypertrophic scar after burn: a randomized controlled trial [33].	Korea	To evaluate the effect of burn rehabilitation massage therapy on hypertrophic scar after burn.	Randomised controlled trial Comparison between two groups; intervention (those who received burn rehabilitation massage) and control (those who did not)	n=146 (111 men and 35 women)(76 intervention – massage group; 70 control group)	Control group-standard therapy for scar management. The standard therapy comprised range of motion (ROM) exercise for the prevention of burn scar contracture, silicone gel application, pressure therapy, corticosteroid injection, and application of whitening cream, anti-redness cream, and moisturizing oil for	Significant (at $p < 0.05$) decrease in scar pain, scar thickness, scar melanin, scar erythema and scar transdermal water loss in intervention group were reported immediately after intervention/usual care that is average of 3.5 months post injury.	Reports outcome measure in details however methods on time of intervention and outcome measure not very clear. Long term effects of massage therapy could not be identified. Evolution of hypertrophic scars was not considered.	Suggests: further research to compare effects of massage therapy on older and new scars.

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Table 2 (continued)

Study	Country	Aim/focus	Study type	Participants	Intervention	Outcome	Limitations	Comment
					hypertrophic scar management. Intervention group additionally received 3 sessions of 30 min massage therapy each week for 4 weeks.			
Speech and swallowing rehabilitation following burn injury: role of speech pathologists in multidisciplinary team [32].	India	To educate burns care team on inclusion of Speech and Language Pathologists (SLPs)	Descriptive review Practical guidelines provided for use by medical facilities.	N/A	N/A	SLPs could help in the treatment of dysphagia, cognitive-linguistic deficits, dysphonia, multisensory coma stimulation program, and developmental milestones of the burnt child.		Suggests: active involvement of SLPs in acute and long term management of burns.
Impact of supportive psychotherapy on burns patients [37].	India	To study impact of psychotherapy on depression and body image of burns survivors	Pre-post design Non-experimental. Pre-test post-test design. Participants completed 2 instruments for assessing depression/ body image within 72h of admission with a burn injury, 1 week after discharge and 1 year following discharge.	n = 35 (20 men and 15 women)	Assessment of depression using Beck Depression Inventory, and Assessment of Body Image using The Satisfaction with Appearance Scale- assessments done twice with a gap of one year. 15–20 brief psychotherapy sessions including tele communicative support was given to the survivors when they came to the hospital for wound dressing and follow ups.	Psychotherapy helped reduce depression and improve body image significantly (at $p < 0.05$) for both males and females.	No comparison group.	The results highlight the need for psychotherapy sessions along with standard burn management.
A clinical study of post burn contracture of axilla and its management [28].	India	To study axillary contractures based on age, sex, years of post-burn, based on anatomy distortion, and on severity of functional limitation, surgical option used and its complications with follow up of patient	Prospective follow-up study All patients who underwent surgery to treat axillary post burn scar contracture over a 2.5 year period were documented.	n = 31	Surgery for axillary contracture release, using flaps and grafts. Passive physiotherapy. Active exercises after one month of surgery. Aeroplane splint within 6 months of surgery. Scar massage. Skin graft massage.	Younger females reported higher numbers of axillary contractures. As compared to skin grafts, using flaps for contracture release caused significantly (at $p < 0.05$) less complications and lesser occurrences of re-contracture.	No comparison group.	Interventions were multiple including changes in operative technique, exercise, splinting and massage. No comparison group. Authors reported poor compliance with physiotherapy and splints.

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Table 2 (continued)

Study	Country	Aim/focus	Study type	Participants	Intervention	Outcome	Limitations	Comment
		and patient compliance						
Functional Outcomes of Burn Patients With or Without Rehabilitation in Mainland China [34].	China	To evaluate the functional outcomes of moderate to severe burn patients with and without rehabilitation in terms of self-care performance and quality of life (QOL)	Clinical trial Comparison between two groups; intervention (those who received comprehensive rehabilitation interventions in addition to standard clinical interventions) and control (those who only received standard clinical interventions)	n=55	Patients with total burn surface area of 30% or more were divided into two groups: rehabilitation and conventional care groups. The rehabilitation group underwent comprehensive rehabilitation interventions (e.g., occupational therapy, physiotherapy, and patient and family education) in addition to standard clinical interventions received by the conventional care group.	At 3 months, significant improvements were found in self-care performance (MBI), all dimensions of QOL, pain, and sled depression scale in the rehabilitation group (all $p<0.05$). In the conventional care group, significant improvements were found only in MBI, the physical health dimension of QOL and pain. Group comparisons showed that the rehabilitation group had significant improvements in all measures.	This study used convenience sampling and not random sampling.	Moderate to severe burn injuries can benefit from rehabilitation interventions in terms of physical health, mental health, performance of daily living, and QOL.

studies, results were summarised in a narrative synthesis and no meta-analyses were performed.

Of the 17 studies identified, 12 were descriptive accounts of burn rehabilitation services, including two retrospective reviews of patient records [21,22], three quantitative surveys [23–25], two case studies [26,27], one prospective follow-up study [28], two qualitative studies [29,30], and two descriptive reviews [31,32]. Only five studies evaluated the effectiveness of rehabilitation services — this included one randomised controlled trail of a massage therapy intervention [33], one clinical trial of a comprehensive rehabilitation program comprised of occupational therapy, physiotherapy and education for patients and carers [34], one comparison study investigating rehabilitation outcomes following intensive physiotherapy consultations provided in addition to standard medical care [35], and two pre-post design studies; one evaluating a scar management program [36] and a second reviewing the effect of psychotherapy sessions on mental health outcomes of burns patients [37]. There were seven studies from India [22,26,28,29,31,32,37], two each from China [23,34], Korea [33,36] and Iran [30,35], and one each from Sri Lanka [21], Pakistan [25] and Brazil [24].

3.1. *Descriptive studies of burns rehabilitation services*

A retrospective review of medical records for 459 children admitted to a specialised burns unit at a paediatric hospital in India [22] reported on patient health outcomes and rehabilitation needs. The study investigated the relationship between-age, aetiology, total body surface area (TBSA) burnt, social and economic status and requirements for rehabilitation however, approaches to analysis were not well documented. The study highlighted important issues around access to treatment and the needs of children of lower socioeconomic status. Financial constraints were reported as a major barrier to accessing comprehensive rehabilitation, with 80% of the study population classified as 'below the poverty line'. It is noted that children with higher education had better access to rehabilitation, including psychosocial rehabilitation. One third (n=151, 33%) of patients were from distant peripheral areas outside the capital city, making rehabilitation services costly to reach.

A second study retrospectively reviewed medical records for 46 patients with burns resulting from acid assaults in Sri Lanka [21]. The study reported less than 40% compliance with attendance at rehabilitation clinics however, reasons for non-compliance were not reported. The authors hypothesized that stigma, scarring, and social barriers, including the potential threat of a recurrent incident, were underlying factors for poor attendance. Rehabilitation compliance for long-term follow-up was better among females than males.

A survey of 39 Burns Centres across China [23] was performed, of which 38 reported to provide at least one type of rehabilitation service. The most common rehabilitation services offered were pressure garment provision (n=38, 100%), splinting (n=32, 84%), physical therapy (n=82%) and occupational therapy (n=21, 55%). The study highlighted several challenges to accessing appropriate burn rehabilitation services. These included a shortage of suitably qualified rehabilitation health professionals, a need for professional development and training, an absence of guidelines, and insufficient government funding.

A case study of two paediatric burns patients who received surgery in Taiwan [27] reports on the feasibility and utility of telemedicine for rehabilitation in an island setting, where access to rehabilitation services is a limited. The study evaluated range of motion in the limbs of both patients up to 10 months post-surgery, but no other objective measures were taken. Both patients and surgeons reported to be satisfied with videoconferencing as a method of follow-up consultation. A second case study from India [26] provides a detailed description of the burns treatment and rehabilitation protocol at one urban hospital. Case studies of two women, aged 30 and 35 years, who were treated at the hospital for accidental burn injuries sustained at home, are presented to illustrate hospital procedures. The article reports rehabilitation services to be negligible or non-existent. It states that private burn facilities are scarce and unaffordable for most patients, while government facilities are frequently over-capacity and under-resourced, causing the discharge of patients prior to treatment completion.

A cross-sectional study from Brazil [24] of 63 teenagers and young adults receiving psychological and physical rehabilitation for burn injuries, found low levels or an absence of depression (average Beck's Depression Inventory (BDI) score=7.6, reflecting slight depression) and/or issues with low self-esteem (average score on the Rosenberg Self-Esteem Scale (RSE)=8.4, reflecting an adequate degree of self-esteem). The study suggests that multidisciplinary rehabilitation programs may be effective for ensuring better psychosocial outcomes for burns patients. This study was limited due to its small sample size, use of convenience sampling to select the study population, lack of control group, and lack of information on individual burn severity and associated mental health outcomes. Therefore, study outcomes should be interpreted with caution.

Two qualitative studies were included, which explored the rehabilitation care process for burns patients and their carers. A study from Iran [30] used 28 semi-structured interviews to understand perceptions of patients and carers following self-immolation, identifying the need for integrated rehabilitation care. The second study from India [29] used 22 semi-structured interviews to investigate parental involvement in the rehabilitation care process for children with burn injury. Parents were found to identify and mobilise resources for their child's treatment, manage wounds and perform other tasks associated with rehabilitation in the home, and minimise their child's exposure to stigma within the community. The authors identified a lack of support for parents from health care professionals and other extended family members.

One Indian study [31] reviewed different approaches by rehabilitation practitioners to improve the design of axillary splinting devices to increase patient adherence. Structural physical barriers, such as narrow corridors, were reported to create difficulties for patients wearing the devices.

3.2. *Studies evaluating effectiveness of burns rehabilitation services*

3.2.1. *Impact of rehabilitation on functional outcomes*

One study from Iran [35] compared the outcomes of two burn rehabilitation treatment protocols among 30 burn patients. Patients were allocated into either a control group (n = 15) who received standard medical care, or to an intervention group (n = 15) who received standard medical care with additional intensive physiotherapy consultations. There was a significant difference ($p < 0.01$) in burn contractures between both groups, with one patient (6%) experiencing burn contractures in intervention group and 11 patients (73%) experiencing contractures in the control group.

One clinical trial from China [34] evaluated functional outcomes (self-care and quality of life) of 55 severe burns patients with and without rehabilitation. Patients were allocated into either a control group (n = 25) who received standard medical care, or to an intervention group (n = 30) who received comprehensive rehabilitation including occupational therapy, physiotherapy, and patient and family education. Patient allocation was not random but based on convenience to access rehabilitation services. A wide range of outcome measures were collected at 3 months post intervention, including self-care performance (Modified Barthel Index [MBI]), QOL (World Health Organization Quality of Life-BREF), pain and itchiness (Visual Analogue Scale [VAS]) and mental health (Self-Rating Depression Scale [SDS] and Self-Rating Anxiety Scale). When comparing the intervention and control groups, the intervention group achieved significantly better outcomes in MBI ($p < 0.001$), VAS ($p = 0.009$), physical health ($p = 0.002$), psychological health ($p = 0.021$), and social relationships dimensions of QOL ($p < 0.001$). No confidence intervals were reported for p values.

3.2.2. *Burns scar rehabilitation*

One study from Korea [36] evaluated a scar management program, reporting measures of skin status, depression, and burn-specific health among 26 burns survivors. Participants were allocated into either a control group (n = 13) who received standard medical care, or to an intervention group (n = 13) who received the scar management program over a three month period. There were no significant changes in burn scars, subjective skin status, or depression between the control and intervention groups. Participants within the intervention group observed a reduced burn scar depth over the study period, although this change was not significant. A second randomised controlled trial from Korea [33] evaluated the effect of massage therapy performed by a skilled therapist on hypertrophic burn scars. This study had a large sample size (n = 146), with 76 participants allocated to an intervention group who received massage therapy in addition to standard medical care. The study found significant improvements in scar pain (95%CI: 0.69–2.02; $p < 0.001$), scar thickness (95%CI: 0.03–0.09; $p = 0.02$) and scar melanin (95%CI: 12.1–21.3; $p = 0.02$) between the control and intervention groups following massage therapy.

3.2.3. *Psychological rehabilitation*

One study from India [37] assessed the impact of psychological rehabilitation on 35 burns patients. This study evaluated the effectiveness of supportive psychotherapy for burns patients using a pre-post-test design, examining depression as the outcome. Results showed that multiple (15–20), short, face-to-face and tele-psychotherapy sessions led to a significant decrease in depressive symptoms and improved self-image among both males (95%CI: 0.44–1.16, $p < 0.001$) and females (95%CI: 0.4–1.33, $p = 0.001$).

4. Discussion

This review identified a lack of accessible and sustainable burns rehabilitation services within LMICs. Scarce resources, competing health priorities and limited access for rural populations to healthcare facilities were identified as barriers to providing appropriate long-term burns rehabilitation. Due to the small number of studies identified for this review, it was not possible to comment on the effectiveness of existing burns rehabilitation interventions in this context.

Multiple studies included in this review identified areas requiring improvement within existing burns rehabilitation services. Burns rehabilitation services offered through private sectors were reported to be costly, while government services were reported to be over-capacity and under resourced. This issue is not unique to burns rehabilitation, with primary public health facilities from a number of LMICs reported to be less responsive to patients and often lacking in supplies [38]. A lack of appropriately qualified staff and limited professional development opportunities for clinicians were identified as barriers to making appropriate services available. This is particularly concerning as greater numbers of qualified physicians from LMICs migrate to HICs, while training capacity within LMICs remains low [39].

Multiple studies identified the need for a multidisciplinary approach to burns rehabilitation in LMICs, ideally including elements of physiotherapy, occupational therapy, psychological therapy and patient and family education. It was acknowledged that the likelihood of providing access to all services in a resource poor setting is low. Multidisciplinary care has been shown to be an effective approach to improving functional outcomes in the areas of COPD, stroke and palliative care however, its integration into standard medical practice presents many challenges, even in HICs [40].

Successful rehabilitation requires components of health, education, livelihood and social welfare [41]. It is well established that there is an over-representation of psychiatric and psychological disorders in people with burns, with estimates varying between 20% and 75% among adult patients, which may develop during the continuum of care [42]. The focus of most burn rehabilitation research has been on health — primarily physical health. Our search found only two studies [34,37] specifically describing these components with the addition of empowerment, but individual components were not evaluated.

Long travel distances to health facilities and associated travel costs were both identified as barriers to accessing long-term burns rehabilitation services. Recent years have seen a rise in the utilisation and success of community based rehabilitation services and eHealth applications. The World Health Organisation initiated the Community-Based Rehabilitation (CBR) strategy in 1978 [41], which aimed to achieve a multi-sectoral 'bottom-up' approach to providing long-term care in community settings. Practical aspects of the strategy include enabling communities to develop and implement services to ensure they respond to local needs, and promotes the use of local resources (human, financial, material) where possible to increase the likelihood of service sustainability. Randomised controlled trials evaluating community-based mental health rehabilitation programs in LMICs have shown significant improvement in disability levels [43,44]. Whilst isolated vertical programmes for community rehabilitation are not sustainable, developing skills among community health workers in rehabilitation, for all cause disability including traumatic brain injury, spinal injuries, hip fracture, stroke and other communicable and non-communicable conditions is likely to have far reaching impact. Previous studies have identified numerous benefits of eHealth applications in LMIC settings, such as the use of teleconferencing and videoconferencing for diagnosis and follow-up. Outcomes include improved remote patient monitoring, reduced travel and waiting times for patients, improved diagnostic accuracy and clinical efficiency [45].

4.1. *Strengths and limitations*

This review emphasizes the limited research available on rehabilitation options for burns survivors in LMICs. All studies included in this review emphasised the need for burns rehabilitation services, highlighting some common barriers to their operation. The majority of research work in LMICs on the rehabilitation of burns has occurred in the last decade and therefore, all studies included in this review report on recent data.

Overall, the quality of the studies was poor. Limitations included small sample sizes [21,24,35,36], the use of retrospective data [21,22], non-representative participation [23], and an absence of control group [24]. Due to the methodological variations between studies, direct comparisons between outcomes were not possible. Definitions of rehabilitation varied across the studies and few studies reported clear, validated outcomes. As many studies recruited participants from specific medical institutes or hospitals, the generalisability of study outcomes is questionable. It is likely that there are many effective services currently being provided in LMICs that are undocumented and have not yet been evaluated for effectiveness.

5. Conclusion

The limited published research on known burns rehabilitation practices in low- and middle-income countries highlights a number of barriers to the provision of high quality, accessible and sustainable rehabilitation services. Although a number of studies reported on various treatment practices trialled with small numbers of patients, many of which were shown to improve patient outcomes, interventions varied and evidence on effectiveness is unclear. Few studies provided suggestions on how to incorporate these treatment options into health service protocols, or into the broader health system. As only a small number of studies were identified through this review, further research is required to investigate undocumented burn rehabilitation services, evaluating their effectiveness, feasibility, sustainability and potential for upscale.

Conflict of interest statement

The authors declare that they have no conflict of interest.

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Appendix 3 - Keyword (and subject heading) search strategy

telehealth OR telemedicine OR telesurgery OR telepaediatrics OR telepediatrics OR teleoncology OR telepsychiatry OR telepharmac* OR videoconferencing OR "video-conferencing" OR "remote consultation" OR "remote monitoring" OR telenursing OR telecare OR ehealth OR "ehealth" OR telecommunication* OR telerehabilitation OR teleconsul* OR teleradiology OR telecardiology OR teleopthalmology OR teledermatology OR "information and computer technologies" OR ict OR "information technology" OR telemonitoring OR "computer-based" OR "computer based" OR "distance medicine" OR "remote medicine" OR internet AND indigenous OR eskimo OR aborigin* OR "native American" OR indian OR native OR maori OR "torres strait islander" OR "pacific islander" OR islander OR "first nation*" OR "first people*" OR inuit OR metis OR saami OR sami OR ainu OR aynu OR lapps OR laplander AND "chronic disease*" OR "chronic condition*" OR "chronic illness*" OR "chronic management" OR "complex disease*" OR "complex condition*" OR "complex illness*" OR "complex management" OR "chronic complex" OR "chronic and complex" OR "self-management" OR "self management" OR "self monitor*" OR "self-monitor*" OR "follow-up care" OR "long-term care" OR "follow up care" OR "long term care" OR "primary health care" OR phc OR "primary care" OR "chronic kidney disease" OR ckd OR "kidney disease" OR "cardiovascular disease" OR cvd OR "coronary artery disease" OR cad OR "heart disease" OR "heart failure" OR "chronic heart failure" OR "chronic cardiac failure" OR ccf OR "congestive heart failure" OR chf OR diabet* OR "type 2 diabet*" OR "type ii diabet*" OR iddm OR niddm OR "mental health" OR "mental illness" OR "social and emotional wellbeing" OR "social and emotional well-being" OR sewb OR "psychiatric disease" OR "psychiatric condition" OR "psychiatric illness" OR "psychiatric management" OR depression OR anxiety OR "cognitive behavioural therapy" OR cbt OR "narrative therapy" OR "chronic obstructive pulmonary disease" OR copd OR "respiratory conditions" OR "lung disease" OR asthma OR cancer OR "wound care" OR "wound management" OR burn* OR disability OR injur* OR rehab* OR "brain damage" OR "brain injury" OR "spinal injury" OR stroke OR "cerebrovascular accident" OR cva OR "liver disease" OR hepatitis OR "ear disease" OR "otitis media" OR om OR "noncommunicable disease*" OR "communicable disease"

Appendix 4 - Data extraction tables for 'effectiveness' of telehealth

Study *Level of Effectiveness* & Grade of Recommendation***	**Aim**	**Study Design**	**Participants n=X (% participants Indigenous)**	**Indigenous People Home Land**	**Telehealth intervention**	**Chronic Conditions / Management**	**Health outcome**	**Limitations of study**	**Comments**
Buckley and Weisser 2012 4.c, B	Determine if addition of video link for mental health assessment would change probability of being transferred to the central mental health unit.	Retrospective pre/post intervention analysis Quantitative	*n*=1943 (6.5%)	Aboriginal and Torres Strait Islander Australia	Video-conferencing for assessment	Mental Health	After intro of video-conferencing % of transfers fell 66.8% (95%CI 64.0 to 69.5) to 59.6% (95%CI 56.1 to 63.1). Adjusting for age, sex, clustering in hospitals and repeat visits odds of transfer were 0.69 (95%CI 0.49 to 0.97) of previous.	No randomisation to control or treatment group.	Infers that patients are not being transferred unnecessarily from home community. No outcome to suggest better/worse health, however receiving treatment at home, on country, may lead to better health outcomes.
Fredericks, Clark 2013 4.c, B	Subsidiary aim: examine 'app' effectiveness on client knowledge and self-care.	Pre/Post Pilot study with evaluation by before and after questionnaires	*n*=5 (100%)	Aboriginal and Torres Strait Islander Australia	Introduction of IT 'app' for monitoring and self-care	Health Failure	Knowledge of disease improved by 13%. Self-care behaviours increased 3.2%.	Small sample.	
Lorig, Ritter 2010 1.c, B	Effect of online Diabetes self-management program on patient outcomes.	RCT. Patients randomised to: 1) the program 2) the program with e-mail reinforcement 3) were usual-care control	*n*=73 (100%)	American Indian / Alaskan Natives United States of America	Online self-management program	Diabetes	AI/AN showed improvements in health distress and activity limitation compared with usual-care control subjects. Demonstrated stronger improvement in HbA1C. Email reinforcement showed no better improvement.	Participants were already seeking information about disease; therefore may influence outcomes. AI/AN group offered program after 6 months; may have contributed to beneficial health outcomes.	
Mansberger, Gleitsmann 2013 1.c, B	Effectiveness of **telemedicine** for providing diabetic retinopathy screening examinations compared with traditional	RCT. Assigned diabetic participants to one of two groups: 1) telemedicine with a nonmydriatic camera	*n*=567 (16.8%) (high proportion of minorities)	American Indian / Alaskan Natives United States of America	Telemedicine with a non-mydriatic camera	Diabetic Retinopathy	Telemedicine group more likely to receive screening within first year of enrolment compared with the traditional surveillance group	Short study period. Diabetic retinopathy requires life-long surveillance, long-term follow-up is critical to evaluating the effectiveness and	

Study *Level of Effectiveness* & Grade of Recommendation***	**Aim**	**Study Design**	**Participants n=X (% participants Indigenous)**	**Indigenous People Home Land**	**Telehealth intervention**	**Chronic Conditions / Management**	**Health outcome**	**Limitations of study**	**Comments**
	surveillance. One year.	2) traditional surveillance with eye care provider.					(94% versus 56%, p < 0.001).	sustainability of telemedicine.	
Mansberger, Sheppler 2015 1.c, B	Compare **telemedicine** to traditional eye examinations in ability to provide diabetic retinopathy screening examinations	RCT. Randomised and followed up to 5 years.	*n*=567 (16.8%)	American Indian / Alaskan Natives United States of America	Telemedicine with a non-mydriatic camera	Diabetic Retinopathy	Telemedicine group more likely to receive screening compared with traditional group during the 6-month or less (94.6%[280/296] vs 43.9% [119/271]; 95%CI, 46.6%-54.8%; P < .001) and greater than 6-month through 18-month (53.0%[157/296] vs 33.2%[90/271]; 95%CI, 16.5%-23.1%; P < .001) time periods.	Study population included high % of transient housing and health care access. Consequently, communities that display more stable housing may actually observe higher percentages of patients receiving long-term follow-up. Monetary incentive provided may increase follow-up.	
Reeve, Thomas 2014 4.c, B	Compare ear health care after implementation of ear health program using **telehealth.**	Retrospective. Pre/post intervention analysis evaluation Descriptive	*n*=172 (100%)	Aboriginal Australia	Otoscopic images integrated into existing service	Otitis Media	Decreased wait time for specialist review despite increased referral rate. No outcome regarding management of disease or better/worse health.	Retrospective data entered by different individuals. Database relies on input from individual operators. No control.	Essential information available electronically allowed for triaging of cases and clinical decision-making even when patients absent during telehealth consult.
Riley, Keberlein 2015 3.d, B	Evaluate effects of program on healthcare utilisation. Cost evaluated, but not reported on.	Comparison. A matched cohort was identified for comparison.	*n*=90 (31.1%)	Native American United States of America	Mobile, broadband-enabled remote monitoring devices.	Heart Failure	At 6 mths following enrolment hospitalisations decreased 42%, from 3.3 to 1.9 admissions; days hospitalised decreased 64%, from 14.2 to 5.2 days. Comparably significant reductions at 30 and 90 day periods prior	Limited evaluation of small pilot program, with no randomisation. Unable to conclude that remote monitoring program could produce effect.	Changes to services may have contributed to beneficial outcomes being evident in control group. Patients were satisfied. Patient satisfaction ratings had no clear methods, was not identified as aim,

Study *Level of Effectiveness* & Grade of Recommendation***	**Aim**	**Study Design**	**Participants n=X (% participants Indigenous)**	**Indigenous People Home Land**	**Telehealth intervention**	**Chronic Conditions / Management**	**Health outcome**	**Limitations of study**	**Comments**
							versus following enrolment. Reductions were not significantly greater compared with matched cohort.		not included in Indigenous peoples' acceptability.
Robertson, Kattelmann 2007 4.c, B	Test a culturally appropriate Internet-based interactive program on better Diabetes control.	Comparison. Pilot study. Intervention implemented for 24 weeks, data collected at baseline and follow-up. Data input from participants ongoing.	*n*=52 (100%) (n=33 intervention, n=19 control)	American Indian United States of America	Interactive internet-based support	Type 2 Diabetes	Mean change in HbA1c from baseline to completion was significantly greater for intervention group than for control group (P=.025). No other measures had statistical significance.	Small, convenient sample. No randomisation. Based in one tribe community. Incomplete data set. Participants self-reported dietary intake may contain inaccuracies.	Study suggests improved disease control and program effectiveness. Portal had input from tribal elders on the title, colours and graphics, and content. May have influenced effectiveness. Effectiveness may be due to flexibility offered by online nature of program.
Shore, Brooks 2012 4.c, B	Examine use of **telemental** e-health clinic.	Retrospective, pre/post intervention. Descriptive	*n*=85 (100%)	American Indian and Alaskan Native North America	Video-conferencing	Mental health (focus on PTSD)	Increased prescription drug treatment. 22% before, 60% after	No control, no randomisation. Retrospective data.	
Turner, Robinson 2013 4.c, B	Examine impact of social support messages on patient health outcomes.	Non-randomised prospective study.	*n*=41 (100%) (Patients received a total of 618 e-mail messages from their healthcare provider).	American Indian, Alaskan Native, Native Hawai'ian Northern America	Web-based monitoring and messaging system.	Type 2 Diabetes	Patient HbA1c showed significant improvement from baseline to follow-up. Emotional social support messages were associated with significant decreases in HbA1c values. Patient involvement with system, measured by system login frequency and frequency of uploaded BGL scores to HCP, did not predict change in HbA1c.	Small sample. Non-randomised. No comparison/ control. Messages perceived as supportive by researchers, not by participants. Other variables that impact HHbA1c were not accounted for.	

Study *Level of Effectiveness* & Grade of Recommendation***	**Aim**	**Study Design**	**Participants n=X (% participants Indigenous)**	**Indigenous People Home Land**	**Telehealth intervention**	**Chronic Conditions / Management**	**Health outcome**	**Limitations of study**	**Comments**
Venter, Burns 2010 *(Also in health service feasibility AND client acceptability)* 1.c, B	(1 of 4 aims) Investigate the effect on health outcomes of **telehealth** monitoring and early intervention.	RCT. 12-month pilot trial of home telemonitoring. Patients randomly assigned to control and intervention.	*n*=20 (100%) (10 control, 10 intervention)	Maori New Zealand	Telehealth terminal installed in home, with online link to web portal reviewed regularly by nurses.	Congestive heart failure, chronic obstructive pulmonary disease	Non-significant reduction in mortality. Improved self-reported QOL. (Difference in K10 scores significant 13.6 v's 20.3 (P<0.02). No change in mean blood pressure, FEV1, heart rate, blood oximetry and bodyweight.	Limited sample size	

*Table 1: Level of Evidence for Effectiveness
**Table 2: Grade of Recommendation

Appendix 5 - Data extraction tables for ‘acceptability’ of telehealth by Indigenous peoples

Study *Level of Effectiveness* & Grade of Recommendation***	**Aim**	**Study Design**	**Participants *n* (% participants Indigenous)**	**Indigenous People Home Land**	**Telehealth Medium / Purpose**	**Chronic Conditions / Management**	**Measure of acceptability**	**Acceptability or not of telehealth**	**Limitations of study**	**Facilitators to telehealth**	**Barriers to telehealth**
Arora, Kurji 2013 4.c, B	Determine if **tele-ophthalmology** provided with cultural sensitivity and rituals could overcome social and cultural barriers in ways difficult in the traditional hospital setting.	Descriptive	*n*=5 patients (100%) + 5 HCPs	Aboriginal Canadian	Static images	Ophthalmology	Qualitative interviews	Cultural rituals enhanced satisfaction with program involving telehealth.	Small sample size. Reported acceptability is not only from patient perspective. Although this is the perspective of Indigenous people and healthcare professionals, the responses reflect the people's health journey.	Cultural rituals in program. Program with Indigenous HCP's. Patients admitted they were more trusting of nurses of Aboriginal descent and would therefore be more likely to follow their advice, such as diet-adjusting strategies (p. 61)	Not stated
Doorenbos, Eaton 2010 4.b, B	Assess client satisfaction and acceptability of **telehealth** support group services.	Cross-sectional descriptive	*n*=32 (100%)	American Indian / Alaskan Native United States of America, Alaska	Video-conferencing to facilitate support group	Cancer	6 x 5 point Likert scale items asking about satisfaction. 2 x open-ended qualitative questions.	Satisfied with telehealth as facilitation of support groups	Small, only female, self-reported and selected sample	On-site coordinator knowledgeable about IT	Not stated
Fleming, Dixon 2012 4.c, B	Investigate client views on **computerised therapy** for mental health treatment.	Descriptive	*n*=39 (87%)	Maori, Pacific Islanders New Zealand	Computerised cognitive behavioural therapy	Depression	Focus group methodology using a semi structured interview schedule.	High level of interest in IT programmes to assist with depression.	Small sample size.	Private and confidential health service.	Access to computers
Gibson, Coulson 2011 4.c, B	Explore client perspectives of **telemental** health.	Descriptive	*n*=59 (100%)	First Nations Canada	Video-conferencing for counselling	Mental Health	In-depth qualitative interviews about satisfaction with telehealth	Acceptable? 47% yes, 32% negative, 21% neutral	Small, non-representative, not generalisable.	Initial meeting F2F	IT issues. Not able to develop relationship.
Hiratsuka, Delafield 2013 *(Also in HCP acceptability)*	Examined client’s perspectives of **telemedicine**	Descriptive	*n*=17 (82%)	Alaskan Native / American Indian, Native Hawai’ian	Majority video-conferencing for chronic care management.	Type 2 Diabetes	Focus groups used qualitative interview questions.	No F2F. No connection or relationship between HCP/client.	Small sample, not reflective of population. Limited	HP taking time to talk. Client being comfortable speaking.	Language differences.

Study *Level of Effectiveness* & Grade of Recommendation***	**Aim**	**Study Design**	**Participants *n* (% participants Indigenous)**	**Indigenous People Home Land**	**Telehealth Medium / Purpose**	**Chronic Conditions / Management**	**Measure of acceptability**	**Acceptability or not of telehealth**	**Limitations of study**	**Facilitators to telehealth**	**Barriers to telehealth**
4.c, B	use in primary care.			Alaska, Hawai'i				Liked reduced travel/costs.	generalisability.	Initial consult F2F.	
Jernigan and Lorig 2011 4.c, B	1 of 4 aims was to assess client acceptability and cultural appropriateness of internet-based program.	Descriptive. Report on pilot for larger randomised study.	*n*=27 (100%)	Alaskan Native / American Indian Alaska, United States of America	Internet-based self-management program	Type 2 Diabetes	Semi-structured interview about usefulness, cultural appropriateness, and acceptability	Acceptable	Only people with access to the Internet were included; not representative of population.	Circular model of the curriculum resembled AI/AN concepts of health and wellbeing. Interaction with other AN/AIs was what made the class culturally relevant.	AN/AI were more likely than non-AI/AN to log in to workshop during daytime hours and less likely during evening/wkend hours; may be due to more AI/AN having internet access at work than home.
Mooi, Whop 2012 *(Also in HCP acceptability)* 4.c, B	Assess client level of satisfaction and responses to video-conferencing and **teleoncology**.	Descriptive	*n*=9 (100%)	Aboriginal and Torres Strait Islander Australia	Video-conferencing for referrals, reviews, monitoring.	Cancer	4 x 5 point Likert scale: strongly disagree, to strongly agree. Plus open responses.	Strongly agree or disagree: Quality of VC 96%; Establish Rapport 97%; preference of VC over F2F 97%; Satisfied 87%. Satisfied with video-conferencing overall. Happy to use again.	Small sample size.	HCP adaptive to needs of local community	Privacy and confidential-ity concerns.
Pruthi, Stange 2013 *(Also in HCP acceptability AND service feasibility)* 4.c, B	A program evaluation.	Descriptive	*n*=15 (100%) Random sampling of patients	Alaskan Native Alaska	Telemedicine-based counseling program for high-risk patients with breast cancer	Cancer	5-point satisfaction scale	98% reported good or excellent satisfaction with service.	Small sample size.	Not stated.	Disruptions in information and communica-tion technologies
Shore, Brooks 2008 4.c, B	Compare client acceptability of conducting psychiatric assessments by real-time video-conferencing versus in-	Descriptive	*n*=53 (100%)	American Indian United States of America	Video-conferencing for psychiatric assessments	Mental Health	26 x 5-point Likert scale ranging from a low (negative) score of 1 to a high (positive) score of 5.	94% positive about telehealth, although 45% preferred F2F.	One tribe, limits generalisability	Not stated	Cultural factors. Uncomfortable with IT.

Study *Level of Effectiveness* & Grade of Recommendation***	**Aim**	**Study Design**	**Participants *n* (% participants Indigenous)**	**Indigenous People Home Land**	**Telehealth Medium / Purpose**	**Chronic Conditions / Management**	**Measure of acceptability**	**Acceptability or not of telehealth**	**Limitations of study**	**Facilitators to telehealth**	**Barriers to telehealth**
	person administration.										
Venter, Burns 2012 *(Also in health service feasibility AND health outcome)* 4.c, B	Investigate client's acceptability and usefulness of **telehealth** technology.	Descriptive 12-month pilot trial	*n*=20 (50%)	Maori New Zealand	Touch-screen computer with online link to local nurse for clinical sign input and monitoring	Congestive heart failure, chronic obstructive pulmonary disease	Qualitative interviews. No details provided.	'…the technology was acceptable to most'.	Small sample size. While stated aim to investigate acceptability, methods not provided.	Not stated	Not stated

*Table 1: Level of Evidence for Effectiveness

**Table 2: Grade of Recommendation

Appendix 6 - Data extraction tables for ‘acceptability’ by healthcare professional (HCP)

Study _Level of Effectiveness* & Grade of Recommendation**_	**Aim**	**Study Design**	**Participants _n_**	**Study origin**	**Telehealth Medium**	**Chronic Disease / Management**	**Measure of acceptability**	**Acceptability or not of telehealth**	**Limitations of study**	**Facilitators to telehealth**	**Barriers to telehealth**
Mooi, Whop 2012 _(Also in client acceptability)_ 4.c, B	Assess level of satisfaction and the responses of HCP to **teleoncology**.	Descriptive	_n_=6	Australia	Video-conferencing	Cancer	Seven open-ended questions. Thematic analysis presented by overall descriptive interpretation.	Acceptable due to increasing involvement in care and enabled collaborative approach to care.	Small sample, not representative.	Support from specialist site.	HCP resistant to new IT.
Haozous, Doorenbos 2012 4.b, B	Health professional satisfaction with the **telehealth** system for managing cancer pain.	Cross-sectional descriptive	_n_=56	America	Video-conferencing	Cancer, pain management	Telehealth satisfaction 7pt survey (scale 0 lowest - 4 highest).	Mean 3.35 overall satisfaction.	Small sample, not randomised, no comparison.	Not stated	Not stated
Hiratsuka, Delafield 2013 _(Also in client acceptability)_ 4.c, B	Perspectives of health professionals about the use of **telemedicine** in primary care.	Descriptive	_n_=23 (3 focus groups)	Alaska and Hawai’i	Majority video-conferencing.	Chronic disease management. Type 2 Diabetes	Focus group interviews to elicit opinions, benefits, drawbacks.	Decreased lost clinic time. Depends on reliability of IT.	Small sample, not random, not reflective of population.	IT support. Dedicated IT staff. HCP having socio-cultural awareness and good communication. Initial visit F2F. Continuity of care.	Difficulties with IT. Cultural assumptions.
Gibson, Donnell 2011 4.c, B	Health professionals’ perspectives of **telemental** health.	Descriptive	_n_=63 (survey) _n_=5 (interview)	Canada	Video-conferencing	Mental Health	Survey with 5 point Likert scale. Semi-structured interview.	Usefulness mean 3.3/5. Ease of use mean 3.1/5. Detracts from relationships. Conflicts with cultural expectations. Can't intervene. Not good for clients with paranoia.	Difficult to establish if representative sample.	IT support at facility. Training in telehealth. Initial visit F2F. Using traditional practices (sharing circles). Funds allocated for research.	Difficulties with IT. Poor infrastructure.
Monthuy-Blanc, Bouchard 2013	Explore role of health	Descriptive statistics	_n_=205	Canada	Video-conferencing	Mental Health	Tele-psychotherapy	Perceived usefulness,	Convenience sample may	Not stated	Implication: if telehealth is to

Study *Level of Effectiveness* & Grade of Recommendation***	**Aim**	**Study Design**	**Participants *n***	**Study origin**	**Telehealth Medium**	**Chronic Disease / Management**	**Measure of acceptability**	**Acceptability or not of telehealth**	**Limitations of study**	**Facilitators to telehealth**	**Barriers to telehealth**
4.c, B	professionals' attitudes and perceptions of **telemental** health.	based on quantitative survey data					Acceptance Questionnaire used to measure perceptions of use with 7-point Likert scale ranging from ''strongly disagree'' to ''strongly agree''	positively and directly influences attitudes toward video-conferencing and intention to use.	not be representative of population. Heterogeneity of mental health workers.		be used, an essential prerequisite is HCP's finding it useful.
Kim and Driver 2015 *(Also in health service feasibility)* 4.c, B	Develop, implement and evaluate service delivery model.	Descriptive	*n*=11	Canada	Asynchronous	Diabetic Retinopathy	Survey	Mostly satisfied with teleopthalmol-ogy	Small sample. Not representative. 50% response rate.	Employment of First Nations people.	Not stated.
Pruthi, Stange 2013 *(Also in health service feasibility AND client acceptance)* 4.c, B	A program evaluation.	Descriptive	*n*=8 A random sample of 8 referring physicians	Alaska	Video-conferencing	Telemedicine-based counseling program for high-risk patients with breast cancer	Survey	98% reporting good and excellent satisfaction with the quality of the consultation and addressing patient questions and concerns.	Small sample. Methods not reported.	Not stated	Not stated
Brooks, Manson 2012 *(Also in health service feasibility)* 4.c, B	Understand factors affecting diffusion of telehealth clinics.	Descriptive	*n*=39	United States of America	Video-conferencing	Mental Health	Semi-structured interviews.	Initial impression 67% positive, 10% mixed, 15% sceptical. Over time, more positive. Took average 8 mths to feel routine. 46% HCP said telehealth increased interactions with community.	Small sample. No interview guide.	Community having trust in service and hiring on-site staff aware of cultural needs of community.	Staffing issues; telehealth protocols; trust and acceptance by staff; patient transportation and recruitment.

*Table 1: Level of Evidence for Effectiveness
**Table 2: Grade of Recommendation

Appendix 7 - Data extraction tables for health service ‘feasibility’

Study *Level of Effectiveness** *& Grade of Recommendation***	**Aim**	**Study Design**	**Participants n=X (% participants Indigenous)**	**Indigenous People Home Land**	**Telehealth intervention**	**Chronic Conditions / Management**	**Outcome**	**Limitations of study**	**Comments**
Eriks-Brophy, Quittenbaum 2012 4.c, B	Examine scoring bias with video-conferencing for speech and language assessments with culturally diverse populations.	Comparison between off-site and on-site assessments Pilot study	*n*= 7 (100%)	Aboriginal Canada	Video-conferencing for diagnosis of speech and language disorders.	Communication and behavioural disorders. (It is not clear if this is a chronic disease, however some of these disorders have the potential to require long term management, and care).	Unable to determine if information and communication technologies introduces biases in speech and language assessment. Other biases continue to exist with information and communication technologies.	Small sample. One community. Non-randomised.	**Facilitators:** HCP familiar with information and communication technologies. Trained HW in community. On-site HW for cultural information.
Friedman, Downing 2007 4.c, B	Determine whether adequate examinations could be obtained with remote CT colonography screening program.	Intervention	*n*=321 (unclear, likely 100%)	Native American United States of America	Asynchronous	Cancer screening	Almost 92% acceptable levels for screening of images. “CTC can be introduced to rural underserved communities, performed locally, and interpreted remotely with satisfactory performance, thereby increasing colorectal cancer screening capacity” (p. 1110).	Not randomised (although not feasible). No comparison group.	
Kim and Driver 2015 *(Also in HCP acceptability)* 4.c, B	Develop, implement and evaluate service delivery **teleopthalmology** service.	Descriptive to assess quality, productivity and access.	*n*=7 (100%)	First Nations Canada	Asynchronous	Diabetic Retinopathy	6/7 strongly or moderately agreed with the following statements. Increased: HCP productivity; continuity of care; HCP efficiency; HCP decision making ability.	Small sample, not representative.	**Facilitators**: Capacity building and empowering First Nations people to be involved in the program enhanced success.

Study *Level of Effectiveness* & Grade of Recommendation***	**Aim**	**Study Design**	**Participants n=X (% participants Indigenous)**	**Indigenous People Home Land**	**Telehealth intervention**	**Chronic Conditions / Management**	**Outcome**	**Limitations of study**	**Comments**
Levine, Turner 2009 3.e, B	Determine if patient–HCP interaction via web-based Diabetes management system may increase patient monitoring of blood glucose levels.	Non-randomised, prospective feasibility study.	*n*=109 (100%)	Native American Alabama, Idaho, and Arizona	Web-based Diabetes management application that allowed interaction between patients and HCPs.	Type 2 Diabetes	HCP interaction using web-based system is positively related to frequency of BGL level monitoring.	No comparison group.	Although an increase in BGL monitoring may account for enhanced Diabetes control, this study did not assess control and therefore is not a health outcome for the patient.
Pruthi, Stange 2013 *(Also in HCP acceptability AND client acceptance*) 5.c, B	Primary aim was to assess logistics of secure **telemedicine** connection and sustainability of a business model.	Pilot study to describe feasibility.	N/A	Alaskan Native Alaska	Interactive audio and video telemedicine program	Counselling program for breast cancer risk-reducing strategies	Allocation of resources resulted in equivalent service delivery.		**Facilitators**: Institutional collaboration. Dependable technology.
Smith, Perry 2006 4.c, B	Compare accuracy of ENT assessments face-to-face with pre-recorded information.	Comparison between F2F specialist consult notes, with notes and images.	*n*=58 (93%)	Aboriginal Australia	Asynchronous	Ear health (Otitis Media)	Diagnosis identical in 81% of cases and management identical in 76% of cases. (Differences due to clinical histories taken and clinical examination.)	Reviewed by only one independent specialist. Not randomised.	Discrepancies cannot be automatically assumed to result from the telemedicine technique itself.
Haozous, Doorenbos 2012 *(Also in HCP acceptability)* 4.b, B	Determine the providers' pain management competence after participating in case-conferencing via **telehealth**.	Comparison. Cross-sectional. Descriptive.	*n*=64 (100%)	American Indian / Alaskan Native United States of America	Video-conferencing	Cancer-related pain management	Providers who attended case conference session scored significantly higher ($p<0.01$) on perceived competence regarding pain (mean 25.75) compared with comparison group of providers who did not attend telehealth case conferences (mean 23).	Pre-tests and post-tests were not implemented - would have better measured changes in perceived competence, and results would be valuable for future studies. No randomisation.	
Venter, Burns 2012 *(Also in health outcome AND client acceptance)*	Investigate the effect of **telehealth** monitoring and early intervention	12-month pilot trial. Patients randomly assigned to the control and	*n*=20 (100%) (10 control, 10 intervention)	Maori New Zealand	Telehealth terminal installed in home, with online link to web portal, reviewed	COPD/CHF	Telehealth remote monitoring did not demonstrate benefits in	Limited sample size. Was the disease management programme	

Study *Level of Effectiveness* & Grade of Recommendation***	**Aim**	**Study Design**	**Participants n=X (% participants Indigenous)**	**Indigenous People Home Land**	**Telehealth intervention**	**Chronic Conditions / Management**	**Outcome**	**Limitations of study**	**Comments**
3.d, B	on health service utilisation and models of care.	intervention groups.			regularly by local nurses, supported by clinical algorithms.		reducing service utilisation.	masking effect of telehealth remote monitoring?	
Brooks, Manson 2012 *(Also in HCP acceptability)* 4.c, B	Understand factors affecting diffusion of telehealth clinics.	Descriptive. Semi-structured interviews.	*n*=39 (100%)	American Indian United States of America	Video-conferencing	Mental health	HCP used existing info/protocols to implement in own health service. Considered useful 4.6 on 1 (low) – 5 (high) scale. Telehealth was easily adopted into existing infrastructure. 46% said increased interactions with community.	Participants having to recall information from up to 3 years ago. Interview questions not applicable for all participants.	Transportation difficulties demonstrate that access issues can still remain with traditional video-conferencing and suggest need for home-based telehealth services.
Elliott, Smith 2010 4.c, B	Describe feasibility of community-based mobile **telehealth** screening service.	Descriptive	n=743 consented and n=442 screened (100%)	Aboriginal and Torres Strait Islander Australia	Asynchronous (Mobile telemedicine enabled ear and eye screening. Children screened for ENT disease and referred where necessary.)	Ear, nose and throat conditions	Increased screening rates. 442 in 6 months compared to previous 2 years of normal service.	Comparisons against retrospective data.	**Facilitators:** Community consultation, engagement and collaboration in all areas of the project were important.
Robinson, Warisse Turner 2011 4.c, B	Assesses relationship between patient–health care provider interaction and health behaviours.	Descriptive Non-randomised prospective feasibility study.	*n*=109 (100%) 924 individual person-centred messages were sent to 109 patients	Native American United States of America	Web-based Diabetes monitoring system.	Type 2 Diabetes	Person-centered messages are the single best predictor of patient involvement with the telemedicine system (as measured by the number of times the patient logged into the system).	No control group.	Logging into the system is a necessary but not a sufficient predictor of patient monitoring and uploading of their blood glucose scores.
Shore, Savin 2007 4.c, B	Examined diagnostic reliability of psychiatric assessment by real-time video-conferencing compared to F2F assessment.	Comparison. Participants randomly assigned over two separate occasions by different interviewers to F2F and real-time interactive video-	*n*=53 (100%)	American Indian United States of America	Video-conferencing for mental health assessment.	Mental Health	No significant diagnosis difference between F2F and video-conference. The majority of kappas calculated (76%) indicated a good or fair level of agreement.	2-week interval between interviews could have introduced symptom changes affecting reliability of diagnoses. Low prevalence of certain disorders precluded	Recognised that it may be difficult to engage individuals with internalising disorders through video-conferencing and thus not enabling HPs to identify

Study *Level of Effectiveness* & Grade of Recommendation***	**Aim**	**Study Design**	**Participants n=X (% participants Indigenous)**	**Indigenous People Home Land**	**Telehealth intervention**	**Chronic Conditions / Management**	**Outcome**	**Limitations of study**	**Comments**
		conferencing within 2 weeks.					Externalising disorders tended to elicit greater concordance than internalising disorders.	meaningful conclusions. High prevalence and comorbidity of most conditions may have complicated the diagnosis of any specific disorder. The ethnic homogeneity limits ability to generalise these findings to other populations.	relevant symptoms.

*Table 1: Level of Evidence for Effectiveness
**Table 2: Grade of Recommendation

Appendix 8 - Cultural safety analysis

Principle	Europe	UK	Australia (WA)	Australia (NSW)	Australia (SA)	Canada
Reflexivity *reflect on practice, mutual respect*	Rigorously evaluated burns services.	Rigorously evaluated burns services to improve efficiency, effectiveness and safety of burns care. Feedback from patients and families on quality of care and experience is required, with mechanisms to receive this feedback and a review process.	Rigorously evaluated provision of care.	Rigorously evaluated provision of care to identify unmet needs and the appropriateness of clinical practice guidelines.	None recorded.	None recorded.
Dialogue *true engagement and consultation*	Family counselling sessions and family/burns team consultations are facilitated. Discharge and rehabilitation is patient centred. Discharge plan goals are agreed upon with family to meet their needs. Discharge information is written and verbal, including illustrations with adjustment made for cultural background. Healthcare professionals listen and answer questions with sensitivity to personal beliefs and values. Care is demonstrated to families prior to discharge.	Families have information about their care and access to an interrupter.	Burns injury prevention strategies include design for remote Indigenous communities using Indigenous language and communication methods.	Patients and their families are central to decision making processes. Care plans are developed in consultation with families and reflect their needs. Family are central to the decision making process. Discharge and rehabilitation is patient centred. Rehabilitation processes consider whole patient and family unit, including community.	None recorded.	Trauma team explain processes and provide comfort. Discharge plan completed in consultation with the family. Written information available to take home.
Power *minimising power differentials and maintaining human dignity*	Healthcare professionals activate parental coping strategies. Healthcare professional consider non-pharmacological pain interventions.	Mutually agreeable care plans are developed.	None recorded.	Healthcare professionals negotiate care, and facilitate informed decision making.	Healthcare professionals promote confidence in parental ability and psychosocial wellbeing of parents to ensure their optimal ability to care.	Treatment approach and plan prepared with family. Family is provided regular feedback and encouraged to participate in processes. Healthcare professionals prepare the family well for discharge to home.
Decolonisation *acknowledging the key role of a colonising history in contemporary health outcomes for*	Full consideration of patient and caregiver factors and an awareness of the impact, complications and contraindications of various treatment modalities are	Service and healthcare professional compliance with documented standards ensures equitable care.	Prevention strategies use local research and consult with Indigenous communities to develop Indigenous specific burns injury strategies.	None recorded.	Healthcare professionals facilitate a psychosocial assessment that includes past experiences of trauma, family dynamics, cultural and socio-economic factors,	None recorded.

Principle	Europe	UK	Australia (WA)	Australia (NSW)	Australia (SA)	Canada
Aboriginal and Torres Strait Islander peoples	made when implementing scar management regimes. When discharging, healthcare professionals take into account the family's ability to care and the situation at home.		An Aboriginal Health Impact Statement declared it had considered the needs and interests of Aboriginal people.		barriers to coping and family strengths and supports. Healthcare professionals support families with aspects which have been impacted by the child's injury and admission to hospital.	
Regardful care *provide care that is regardful of culture and challenges the status quo of providing care that is regardless of culture*	Burns care, including care plans and patient management, follows a holistic approach. Psychosocial and rehabilitative interventions provide individualised care according to patients' and family needs, with special attention to consideration of culture. Healthcare professionals promote strategies to keep family's everyday routine and social life. Transport is available from hospital to home and for follow-up visits. Health and rehabilitation services are available in the community. Social workers provide ongoing support of a family's social needs, including the facilitation of communication, coordination of resources, financial aspects and issues of employment and relationships.	Families have access to a Patient Advisory Liaison Service or equivalent and spiritual support.	E-health technologies are used to alleviate distance, transport, accommodation and cost issues for families having to travel from rural and remote areas for expert burns care. Burns prevention is considered, such as campfire burns, particularly for the Indigenous 0-4 year age group. Targeted education programmes and resources that are environmentally and culturally appropriate for rural and remote health professional, Aboriginal health workers, Aboriginal health services and Community groups must be developed.	Burns care meets the patient's needs. Burns care follows a holistic approach, including the care plans. The social worker undertakes a thorough psychosocial assessment in order to review family history, cultural and socio-economic factors, risk factors, barriers to coping, as well as family strengths. Availability of step-down or sub-acute facilities that are linked to acute services, particularly for rural and remote patients (that are unable to be discharged to a supported home environment local to the acute burns unit) for ambulatory care services, is necessary. If a peer support program is available, it must take into account geographical location and cultural sensitivity.	The social worker undertakes a thorough psychosocial assessment in order to review family history, cultural and socio-economic factors, risk factors, barriers to coping, as well as family strengths.	Objective of model of care to provide patient and family focused care.

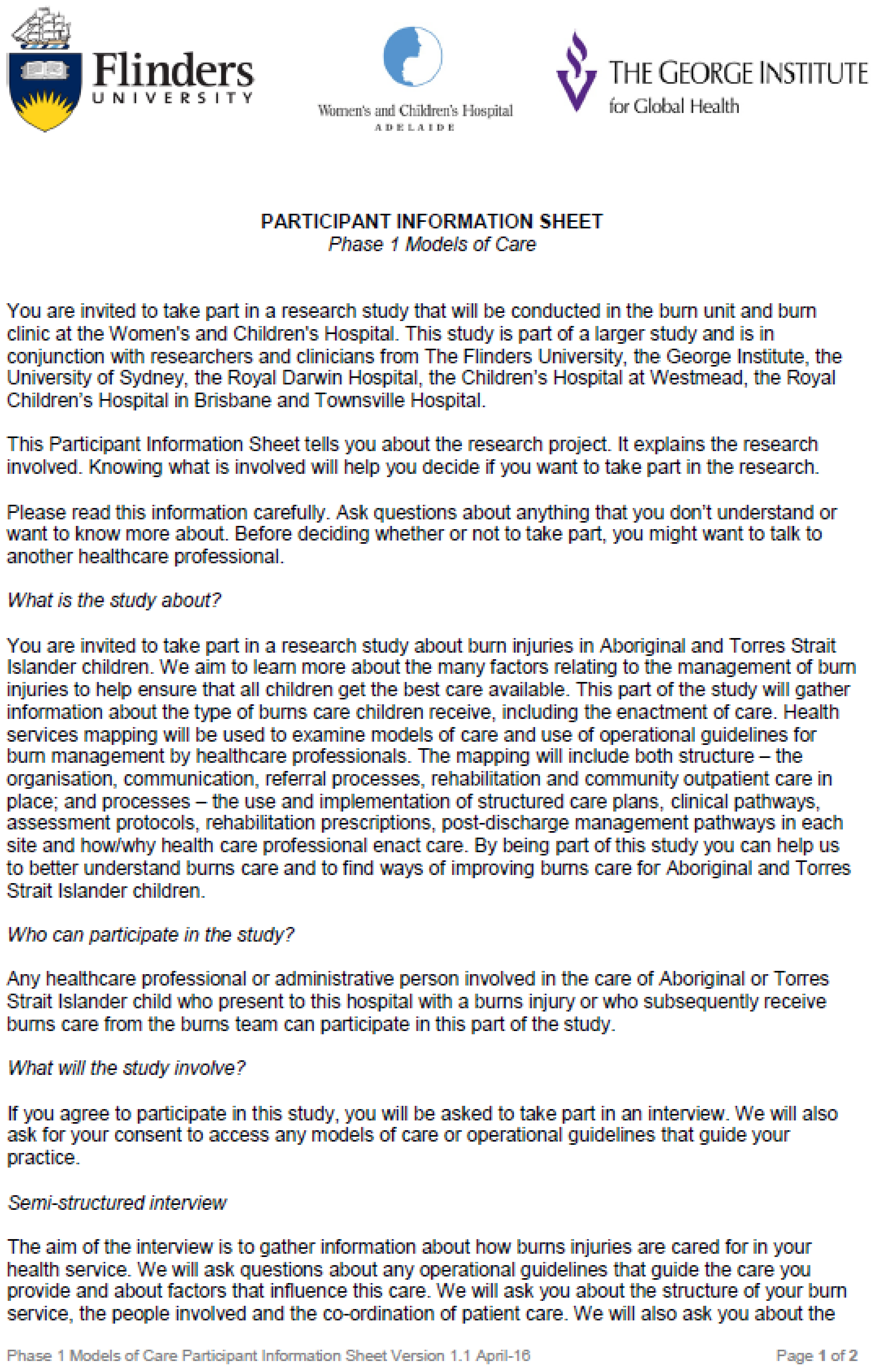
Appendix 9 - NHMRC Standards analysis

Standards	Europe	UK	Australia (WA)	Australia (NSW)	Australia(SA)	Canada
Clinical justification *provide guidance on a clearly defined clinical problem based on an identified need*	Management of a burns injury is considerable and complex, delivered by a multidisciplinary team over a period of time. Burns injury requires specialised care, and co-ordinated care to achieve optimal health outcomes.	It is essential to have a set of standards that are relevant to the current health systems.	A model of care provides guidance to stipulated jurisdiction where burns are a major cause of injury. There is high incidence of burns injury in vulnerable groups, especially in young children. 0-4 years are most at risk. Indigenous peoples experience higher hospitalisation rates for burn related injury compared to non-Indigenous people. Socio-economic factors including low income, single parents, illiteracy, low maternal education, unemployment, job loss, poor living conditions, not owning a home, not having a telephone, and overcrowding all account for greater risk of burns injury. There is increased incidence of burns injury in rural areas compared to metropolitan areas.	Management of a burns injury is considerable and complex, often requiring hospitalisation and extensive and continuous rehabilitation. Identified needs included incidence of burns injury and at risk populations. There is a relative high incidence of burns injury, some resulting in death, and many requiring hospitalisation; with a high proportion of young children requiring hospitalisation.	Management of a burns injury is considerable and complex, often requiring hospitalisation and extensive and continuous rehabilitation.	General references to burns injury requiring specialised services for care.
Multidisciplinary *be developed by a multidisciplinary group that includes relevant experts, end users and consumers affected by the clinical practice guideline*	Developed by three committees, members across several different countries in Europe and comprised medical, nursing and allied health professionals.	Developed by the Burn Care Networks for England and Wales, NHS Specialised Commissioners, Patient Representatives and the British Burn Association. Comments from the wider burns community by circulating the draft revised standards to the BBA membership. Although many people contributed to these revisions the majority of the work was undertaken by an expert multidisciplinary group. Multidisciplinary team	Acknowledged contribution of representatives from the: WA adult and paediatric burns unit; Injury Prevention Working Group; Injury Control Council of WA; WA Drug and Alcohol Office; Kidsafe WA; WA Country Health Service South West Health Region; Royal Life Saving Society WA; and the DoHWA Population Health Division and Health Network Branch.	Input from medical, nursing and allied health clinicians involved in the care of patients with severe burns injury and burns survivors. One consumer was listed.	Listed the paediatric burns service multidisciplinary team; consisting of medical, nursing and allied health.	Contributions and collaboration was with a team of multidisciplinary experts and end users.

Standards	Europe	UK	Australia (WA)	Australia (NSW)	Australia(SA)	Canada
		consisted of medical, nursing allied health, quality consultants, Patient Organisation Representative, burns database personnel.				
Conflicts *include a transparent process for declaration and management of potential conflicts of interest by each member of the guideline development group*	None recorded.	None recorded.	None recorded.	None recorded.	None recorded.	None recorded.
Scientific evidence *be based on the systematic identification and synthesis of the best available scientific evidence*	No systematic process documented.	No systematic process documented.	No systematic process documented.	A health corporation engaged healthcare professionals, managers and the wider community to design, promote and implement.	No systematic process documented.	No systematic process documented.
Recommendations *make clear and actionable recommendations in plain English for health professionals practising in an Australian health care setting*	Provided a set of minimum level burns care requirements, and included checklists and documented the evidence for any recommendations made.	Organised into seven clear sections. Included the evidence required to achieve compliance to the standards.	12 recommendations regarding burns care from an overall jurisdictional service perspective. Recommendations for healthcare professionals were clear, in plain English with flowcharts.	Provided an initial framework outlining model, followed by clear overarching burns injury management recommendations for specific jurisdiction.	Included flowcharts, diagrams and referral documents. Clear clinical care pathways for emergency management, burns wound assessment, wound management, infection control, pain relief and physio/occupational therapy.	Included flowcharts, diagrams, protocols and discharge documents.
Navigation *be easy to navigate for end users*	Document aligned to a literature review	Recommendations made as to how to achieve the standards from a service perspective.	Flowcharts and images.	Clear and set into easily defined areas of burns care recommendations.	Used flowcharts and images, and included referral forms and contact details.	Used flowcharts and included protocol documents for specific healthcare professions.
Consultation *undergo a process of public consultation and independent external clinical expert review*	Invitation to all of those involved in burns care or interested people to expression their opinions.	Sought comments from the wider burns community by circulating draft revised standards to the burn association membership.	None recorded, however proposed model of care only.	Initial development was undertaken by the NSW Severe Burn Service Implementation Group. 2nd edition reviewed by the ACI Burn Injury Network (Statewide Burn Injury Service). Development of the Model of Care included input from medical, nursing and allied	None recorded.	None recorded.

Standards	Europe	UK	Australia (WA)	Australia (NSW)	Australia(SA)	Canada
				health clinicians involved in the care of patients with severe burns injury and burns survivors.		
Dissemination *incorporate a plan for dissemination including issues for consideration in implementation*	None recorded.	None recorded.	Extensive list recorded.	None recorded.	None recorded.	None recorded.

Appendix 10 - Participant information sheet (research part one)



Flinders UNIVERSITY

Women's and Children's Hospital ADELAIDE

THE GEORGE INSTITUTE for Global Health

PARTICIPANT INFORMATION SHEET

Phase 1 Models of Care

You are invited to take part in a research study that will be conducted in the burn unit and burn clinic at the Women's and Children's Hospital. This study is part of a larger study and is in conjunction with researchers and clinicians from The Flinders University, the George Institute, the University of Sydney, the Royal Darwin Hospital, the Children's Hospital at Westmead, the Royal Children's Hospital in Brisbane and Townsville Hospital.

This Participant Information Sheet tells you about the research project. It explains the research involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk to another healthcare professional.

What is the study about?

You are invited to take part in a research study about burn injuries in Aboriginal and Torres Strait Islander children. We aim to learn more about the many factors relating to the management of burn injuries to help ensure that all children get the best care available. This part of the study will gather information about the type of burns care children receive, including the enactment of care. Health services mapping will be used to examine models of care and use of operational guidelines for burn management by healthcare professionals. The mapping will include both structure – the organisation, communication, referral processes, rehabilitation and community outpatient care in place; and processes – the use and implementation of structured care plans, clinical pathways, assessment protocols, rehabilitation prescriptions, post-discharge management pathways in each site and how/why health care professional enact care. By being part of this study you can help us to better understand burns care and to find ways of improving burns care for Aboriginal and Torres Strait Islander children.

Who can participate in the study?

Any healthcare professional or administrative person involved in the care of Aboriginal or Torres Strait Islander child who present to this hospital with a burns injury or who subsequently receive burns care from the burns team can participate in this part of the study.

What will the study involve?

If you agree to participate in this study, you will be asked to take part in an interview. We will also ask for your consent to access any models of care or operational guidelines that guide your practice.

Semi-structured interview

The aim of the interview is to gather information about how burns injuries are cared for in your health service. We will ask questions about any operational guidelines that guide the care you provide and about factors that influence this care. We will ask you about the structure of your burn service, the people involved and the co-ordination of patient care. We will also ask you about the processes of communication between health professionals, the implantation of models of care, and ask questions about your enactment of burns care with Aboriginal and Torres Strait Islander children.

Are there any benefits to me for my participating in the study?

There are no known benefits to you for your participating in this study. We hope that the results from this study will better inform treatment of burn injuries to help ensure that all children get the best care available.

Are there any side-effects and risk associated with this study?

There are no physical side-effects or known risks associated with this study. If you feel uncomfortable with any question during the interview you don't need to answer those questions or we can stop the interview. We can also organise for you to see a counsellor.

Other information

Participation in this project is voluntary and if you decide not to take part or decide to withdraw at any time this will not affect your employment with the heath service or your relationship with those you work in the burns team.

The information you give us will be completely confidential. All the researchers and study staff, Aboriginal and non-Aboriginal, have signed a "Confidentiality" agreement. This means that they agree not to talk about you or about any information you give us, to anyone outside the research team. Your information will remain confidential except in the case of a legal requirement to pass on personal information to authorised third parties. This requirement is standard and applies to information collected both in research and non-research situations. Such requests to access information are rare; however we have an obligation to inform you of this possibility.

Your data will be kept secure on a computer and only the researchers working on this study will have access to the information you provide. Your identity (name and address) will not be kept with your interview answers and records. A report of the study may be published, but no information that could identify you or the health service you are employed will be published.

If you have any questions about the conduct of this study, please do not hesitate to discuss them with Rebecca Ivers on 02 8052 4341 or Sarah Fraser on 08 8273 7200.

This project has been approved by the Aboriginal Health Research Ethics Committee in your jurisdiction and the Women's and Children's Health Network Human Research Ethics Committee.

If you have any concerns or complaints regarding the ethical conduct of the study, you are invited to contact either the Aboriginal Health Research Ethics Committee on 08 8273 7200 or the Women's and Children's Human Research Ethics Committee on 08 8161 6521.

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

This research is funded through a National Health and Medical Research Project Grant (APP1059038) and was initiated by Professor Rebecca Ivers at The George Institute for Global Health, The University of Sydney. This research is being co-ordinated by The George Institute for Global Health and The Flinders University. The researchers for this study are: Professor Rebecca Ivers, Dr Kate Hunter, Ms Julieann Coombes (The George Institute for Global Health and the University of Sydney), Ms Sarah Fraser, Associate Professor Julian Grant, Dr Tamara Mackean (The Flinders University of South Australia) and Dr Warwick Teague (The Royal Children's Hospital and the University of Melbourne).

Appendix 11 - Participant consent form (research part one)

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PARTICIPANT CONSENT FORM

Phase 1 Models of Care

Short Title	Understanding burn injury in Aboriginal and Torres Strait Islander Children
Protocol Number	NH&MRC ID: APP1059038
HREC Number	HREC/14/WCH/65
Coordinating Principal Investigator	Professor Rebecca Ivers
Location	Women's and Children's Hospital
Researcher	Sarah Fraser

I, ………………………………………………………………… (PRINT NAME), give consent to participation in the research project **'Understanding burn injury in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes.'**

In giving my consent I acknowledge that:

- The requirements for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
- I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
- I understand that I can withdraw from the study at any time without affecting my relationship with the researcher(s) and the health service in which I am employed, now or in the future.
- I understand that my involvement is strictly confidential and no information about me or the health service I am employed will be published in any way that reveals my or its identity.
- I understand that being in this study is completely voluntary – I am not under any obligation to consent.
- I understand that the information I give will only be used with everyone's answers pooled together, not my individual answer.
- I understand that I am giving consent for the research team to access the documents that guide burn care in the health service I am employed.
- I understand the privacy and confidentiality of any information I provide will be safeguarded as explained in the Participant Information Sheet except where there is a requirement by law for it to be divulged.
- I understand that if I have any complaints or questions concerning this research project I can contact the principal researcher.

- I understand that if I have any concerns or complaints regarding the ethical conduct of the study, I am invited to contact either the Aboriginal Health Research Ethics Committee on 08 8273 7200 or the Women's and Children's Health Network Human Research Ethics Committee on 08 8161 6521.

Name of Participant (please print) ____

Signature of Participant ______________________________ Date ______________________

I have explained the research project to the participant and believe that he/she understands what is involved.

Researcher's signature and date ____

Appendix 12 - Semi-structured interview guide (research part one)

<u>Health system structure within the tertiary health setting</u> ***(in-patients*****)**

1. How are burn injuries managed in this hospital, and who is involved?
- processes involved regarding the co-ordination of care
- effective communication within the burns team
- processes to enhance communication

2. When does a child (or their family) identify as Aboriginal and/or Torres Strait Islander? Where is this recorded?
- Clarification prior to consulting with the child (and their family)

3. Do you know if this hospital has specific a burns injury model of care? (Ask what they think a MoC is and develop a shared understanding on what a MoC is. Philosophical, multifaceted concept, broadly defines the way services are delivered)
- do you follow any? if so what version, last accessed, ease of accessibility
- have you found that the application of care has been different for Aboriginal and/or Torres Strait Islander children than for non-Indigenous children?
- acceptable care for Aboriginal and Torres Strait Islander children
- additional health care guidelines for Aboriginal and Torres Strait Islander families? Translator?
- opportunities to draw on the strengths of the burns teams collective knowledge, unwritten?

4. Are there specific referral pathways for a child with a burns injury as an in-patient?
- criteria for referral
- pathways you follow
- alternate/extra health professionals/services referred to/involved for Aboriginal and/or Torres Strait Islander families
- application different for Aboriginal and Torres Strait Islander children in comparison to non-Indigenous children?

Health system structure for the tertiary health setting ***(out-patients and long-term care*****)**

5. Who is involved in the out-patient management of a child with a burns injury,

a) how is the long-term care managed?

- processes involved regarding co-ordination of care for outpatients
- effective communication within the burns team and health professionals outside of hospital
- processes to help effective and efficient communication
- specific processes to accomplish follow-up care with patients
- effective communication with patients to enhance understanding
- follow-up care of transient patients
- follow-up care using local Aboriginal and/or Torres Strait Islander Health Workers with local community knowledge to facilitate/co-ordinate care at local hospitals/ACCHOs etc
- effective care for Aboriginal and Torres Strait Islander children

Cultural competency/awareness/safety

6. Has your employer, or any other professional affiliation you may have, provided/offered cultural awareness/competency training?

- what did you think of it?
- principles of cultural safety?

Appendix 13 - Shared learning, data analysis discussion with Ngara Keeler

Ngara said that she could who pick the Indigenous practitioners were. She also knew the non-Indigenous practitioners, who felt there was equality in what they did. Participants said 'we don't do anything different. It is the same care for everyday', however clinicians go on to provide examples of the things they did do differently. Ngara thought clinicians seemed very cautious about presenting themselves as doing something different for different groups of patients. (*I recall feeling similar and remember trying to make the question about providing different care in a way that made clinicians feel safe to answer*). Ngara was surprised that the broader policy documents that exist do not influence or support clinicians in understanding equitable care. (*This links to policies of cultural competency whereby if there is not strong leadership or sufficient resources to drive their implementation, actions will not manifest in the healthcare interaction*).

Ngara felt a broader concept of racism was present. Not overt or deliberate racism, but evident through different cultural base, position and privilege. The language used to describe patients made Ngara feel angry; as example by the use of the word 'lass'. Ngara thought this may have been influenced by a generational gap and not so evident in the younger clinicians.

Specific questions regarding nodes developed by Ngara:

Respect for the role of the ILO/ALO and their value in the MDT?
Nagara was not sure if some health services were better than others, however in this sample of transcripts, one clinician said they didn't even know what they (A/ILO) did. She said this shows a lack of respect and underlying prejudice.

Definition of need for Indigenous versus non-Indigenous clinicians
The ILO/AO have a different perspective of client's needs based on a holistic model of health from their cultural knowledge (*ways of knowing, being and doing*). Whereas the non-Indigenous clinician come from a clinical/medical model. Non-Indigenous clinicians seemed to look only at the burn, whereas the ILO/ALO looked at cultural issues. For example language barriers, relations visiting, other needs. The ALO/ILO comes from the client's perspective of need. The social worker had a similar philosophy and this may have been because of their stated good relationship with the ALO/ILO.

Cultural competence
Training, education, exposure to Indigenous culture will enhance cultural competence. This needs to be reinforced by the system. For example the hospital must support and lead this. There was

limited evidence in these transcripts to support there being evidence of system support to cultural competence.

Cultural brokerage

A role that Indigenous people have between an Indigenous client and a clinician (*a Western position*). The role is to make the client and the Western biomedical model understand each other (*the interface of knowledge systems*). The role is to facilitate a two-ways learning, not just eh conversation, but true understanding (*Ganma*).

Cultural healing practices

Spiritual needs being treated along with Western biomedical needs being treated. This is an example of different care being provided if a service provides this type of care. Understanding cultural healing practices is connected to cultural awareness training (cultural awareness leads a clinician to cultural competence and with a 'space' or 'the resources, can allow for cultural healing practices).

Cultural spiritual beliefs

Sometimes in Indigenous culture beliefs about sickness can be a spiritual problem. The example used in one transcript was about Traditional Singing. The IHP may have mentioned this to make me (Sarah) aware that some Indigenous people have these beliefs and that these beliefs are about the child and family that is being treated, and that an understanding of different believe can help to inform better care.

It is so important to get to the child and family. To have them come on the journey. The journey of care will be difficult if you don't understand where the family is coming from. The child will suffer and the clinicians will not get the result they want. Disjointed understanding (an inability to find an interface). Clinicians need to understand the person and the issues related to being Indigenous and their culture.

Cultural competence

It begins with institutions. The government have been trying. Clinicians need tools and information and more Indigenous people to lead this work. Cultural competence needs a dedicated strategy and buy-in from the top is necessary to embed. There is an example in NT interview where they say the policy makes things easier; however she went on to say people still come to directly to her for assistance. We could question if the policy is appropriately resourced? Indigenous people need to feel welcome. They need to go into a hospital and feel welcome. We live in a white world. An Indigenous face may make all of the difference. Cultural competence in NT is by virtue of location and emersion in culture that cannot be escaped. When it is in your face you have to address it and if you’re addressing it, it means yourre doing it and addressing cultural issues. There is recognition of Indigenous people. Clinicians are forced to do it by virtue of location and population in NT.

Racism

Choosing not to graft due to be a serial absconder. “Long-grasser” is racist. Clinician need to understand the person because some of the trauma that people face. Eg a woman, homeless, unemployed, Aboriginal, no family, no money. In her world she has nothing and now she has been burnt and people wonder why she can’t stay in the hospital. She is absconding for a reason. The racism comes from a place of white privilege. They have never experienced it. There were many examples of terminology and descriptions of clients that clinicians were working with that were racist. Patronizing and paternalistic.

Discharge

Clinicians need information and understanding of where someone ‘comes from’ and must not make decisions on assumptions around discharge. Clinicians need community information and clients need to have a real and thorough understanding of their responsibility to make informed choices.

Appendix 14 - Participant information sheet for family (research part two)

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PARTICIPANT INFORMATION SHEET

Phase 2 Patient Journey Mapping - Family

You are invited to take part in a research study that will be conducted in South Australia and the Northern Territory, through the Burns Unit and Burns Clinic at The Women's and Children's Hospital. This study is part of a larger study and is in conjunction with researchers and clinicians from the Flinders University, the George Institute, the University of Sydney, the Royal Darwin Hospital, the Children's Hospital at Westmead, the Royal Children's Hospital in Brisbane and Townsville Hospital.

This Participant Information Sheet tells you about the research project. It explains the research involved. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about.

What is the study about?

You are invited to take part in a research study about burn injuries in Aboriginal and Torres Strait Islander children. We aim to learn more about the many factors relating to management and treatment of burn injuries to help ensure that all children get the best care available. This part of the study will gather information about the type of burns care your child has received since the burns injury and will record your family's journey. We will also record the process of care followed, and the enactment of care by health professionals. By being part of this study you can help us to better understand the factors that shape burns care and to find ways of improving burns care for Aboriginal and Torres Strait Islander children.

Who can participate in the study?

Any Aboriginal or Torres Strait Islander child who comes to this hospital with a burn and their parent or carer can participate in this study.

What will the study involve?

If you agree to participate in this study, you will be asked to take part in one initial interview, with the possibility of up to two more. We will also ask for your consent to access the medical records of your child, including details of care received at the hospital and elsewhere in relation to the burn.

Interviews

The aim of the first interview is to hear more about yours and your child's journey through the healthcare system. We will ask you to tell us your story about what has happened at the health services you have been to for burns care. For example, we will ask you questions about how you were feeling and what you needed at certain points in your journey. We will also ask you about the care you liked, and if you had any difficulties including such things as money or understanding information. To map your journey as best as possible, we may contact you again to finish your story. We will only contact you up to two more times and only up to one year following your child's burn injury.

Your child's medical records and healthcare professionals

As previously agreed, we will access your child's medical records relating to this burn, including at the hospital, and with your usual medical provider (for example your general practitioner), or those held by other health practitioners involved in the burns treatment. We will not record medical records that are unrelated to care of the burn.

We will also talk the healthcare professionals who were involved in the care your child received for their burn injury. This information will help us to understand the barriers or service gaps that exist for Aboriginal children seeking high quality care.

Are there any benefits for my child participating in the study?

There are no known benefits for your child in participating in this study. We hope that the results from this study will better inform treatment of burn injuries to help ensure that all children get the best care available.

Are there any side-effects and risk associated with this study?

There are no physical side-effects or known risks associated with this study. If you or your child feel uncomfortable with any question or become upset during the interviews you don't need to answer those questions or we can stop the interview. We can also organise for you to see a counsellor.

Other information

Participation in this project is voluntary and if you decide not to take part or decide to withdraw at any time this will not affect your child's care at the Hospital or other health services you access or your relationship with those treating your child in any way.

The information you give us will be completely confidential. All the researchers and study staff, Aboriginal and non-Aboriginal, have signed a "Confidentiality" agreement. This means that they agree not to talk about you or about any information you give us, to anyone outside the research team. Your information will remain confidential except in the case of a legal requirement to pass on personal information to authorised third parties. This requirement is standard and applies to information collected both in research and non-research situations. Such requests to access information are rare; however we have an obligation to inform you of this possibility. If you say anything to the interviewer, or if anything occurs during the interview, that makes him or her worried about your child's safety, they will talk to a social worker at the Women's and Children's Hospital to see if they can arrange some support for you. The researcher will talk to you before doing that. Your data will be kept secure on a computer and only the researchers working on this study will have access to the information you provide. Your identity (name and address) will not be kept with your interview answers and records. A report of the study may be published, but no information that could identify you or your child will be included.

If you have any questions about the conduct of this study, please do not hesitate to discuss them with Sarah Fraser or the Aboriginal Liaison Officer at this hospital.

This project has been approved by the Aboriginal Health Research Ethics Committee and the Women's and Children's Health Network Human Research Ethics Committee.

If you have any concerns or complaints regarding the ethical conduct of the study, you are invited to contact either the Aboriginal Health Research Ethics Committee on 08 8273 7200 or the Women's and Children's Health Network Human Research Ethics Committee on 08 8161 6521.

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

This research is funded through a National Health and Medical Research Project Grant (APP1059038) and was initiated by Professor Rebecca Ivers at The George Institute for Global Health, The University of Sydney. This research is being co-ordinated by The George Institute for Global Health, The University of Sydney. The researchers for this study are: Professor Rebecca Ivers, Dr Kate Hunter, Ms Julieann Coombes and Mr Jake Byrne (The George Institute for Global Health and the University of Sydney), Dr Serigne Lo (The Melanoma Institute), Professor Andrew Holland (The Children's Hospital at Westmead), Professor Roy Kimble (The University of Queensland) and Dr Kellie Stockton (Royal Children's Hospital), Professor Kathleen Clapham and Dr John Daniels (The University of Wollongong) and Ms Delia Hendrie (Curtin University of Technology), Mr Kurt Towers (Northern and Central Adelaide Local Health Districts), Professor Sandra Eades (Baker IDI), Ms Sarah Fraser, Associate Professor Julian Grant and Dr Tamara Mackean (Flinders University) and Professor Belinda Gabbe (Monash University).

Appendix 15 - Participant consent form for family (research part two)

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PARTICIPANT CONSENT FORM

Phase 2 Patient Journey Mapping - Family

Short Title	Understanding burn injury in Aboriginal and Torres Strait Islander Children
Protocol Number	NH&MRC ID: APP1059038
HREC Number	HREC/14/WCH/65
Coordinating Principal Investigator	Professor Rebecca Ivers
Location	Women's and Children's Hospital
Researcher	Sarah Fraser

(Consent Form will be also be explained verbally to the Participant by the Researcher)

I, ... (PRINT NAME), give consent to my and my child's participation in the research project **'Understanding burn injury in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes'.**

In giving my consent I acknowledge that:

- The requirements for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
- I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
- I understand that I can withdraw from the study at any time without affecting my relationship with the researcher(s), the health services from which my child receives care now or in the future.
- I understand that my involvement is strictly confidential and no information about me will be published in any way that reveals my identity, unless I give specific consent for my identity to be revealed.
- I understand that being in this study is completely voluntary – I am not under any obligation to consent. (This means you can say NO.)
- I acknowledge that I am giving consent for the research team to access the medical records of my child, and details of the burn treatment and care for my child from any health care practitioners who has been involved in their treatment. I understand that such information will remain confidential.
- I understand the privacy and confidentiality of any information I provide will be safeguarded as explained in the Participant Information Sheet except where there is a requirement by law for it to be divulged.
- I understand that if I have any complaints or questions concerning this research project I can contact the principal researcher.

- I understand that if I have any concerns or complaints regarding the ethical conduct of the study, I am invited to contact either the Aboriginal Health Research Ethics Committee on 08 8273 7200 or the Women's and Children's Health Network Human Research Ethics Committee on 08 8161 6521.

Name of Child (please print) ____

Name of Parent/Guardian (please print) _________________________________

Signature of Parent/Guardian ____________________ Date __________________

If required:
Name of Witness* to Parent/Guardian's Signature (please print) __________________

Signature of Witness __________________________ Date __________________

* If required, witness is not to be the investigator, a member of the study team or their delegate. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. Witness must be 18 years or older.

I have explained the research project to the participant and believe that he/she understands what is involved.

Researcher's signature and date: ______________________________________

Appendix 16 - Interview guide for family (research part two)

SEMI–STRUCTURED INTERVIEW GUIDE

Phase 2 Patient Journey Mapping – Family

Can you tell me about your family's' journey since your child experienced the burn injury?

Aspects to be discussed and mapped include:

Chronological mapping of services

- Patient/family journey
- Patient/family priorities, concerns, commitments
- Health services priorities
- Service gaps
- Responses to gaps
- Patient history
- Diagnosis/referral
- Trips to health services
- Pre-admission
- In hospital
- Discharge/transfer
- Trip home
- Follow up

Dimensions of health

- Physical/biological
- Psychological/emotional
- Social and wellbeing
- Spirituality
- Cultural Integrity

Impacting Factors

- Location/setting
- Interactions with health system
- Languages/communication
- Financial resources
- Aboriginal/non-Aboriginal

Appendix 17 - Participant information sheet for burns team member (research part two)

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PARTICIPANT INFORMATION SHEET

Phase 2 Patient Journey Mapping – Healthcare Professional

You are invited to take part in a research study that will be conducted in South Australia and the Northern Territory, through the Burns Unit and Burns Clinic at The Women's and Children's Hospital in Adelaide. This study is part of a larger study and is in conjunction with researchers and clinicians from the Flinders University, the George Institute, the University of Sydney, the Royal Darwin Hospital, the Children's Hospital at Westmead, the Royal Children's Hospital in Brisbane and Townsville Hospital.

This Participant Information Sheet tells you about the research project. It explains the research involved. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about.

What is the study about?

You are invited to take part in a research study about burn injuries in Aboriginal and Torres Strait Islander children. We aim to learn more about the many factors relating to management and treatment of burn injuries to help ensure that all children get the best care available. This part of the study will gather information about the type of burns care a child has received since presenting to the health service you are employed with their burns injury.We will record the processes of care followed, and ask questions about your enactment of the care provided.By being part of this study you can help us to better understand the factors that shape burns care and to find ways of improving burns care for Aboriginal and Torres Strait Islander children.

Who can participate in the study?

Any healthcare professional or administrative person involved in the care of the Aboriginal or Torres Strait Islander child who came to this hospital with a burns injury and who subsequently received burns care from the burns team can participate in this part of the study.

What will the study involve?

If you agree to participate in this study, you will be asked to take part in one initial interview, with the possibility of up to two more. We will also access the medical records of the child to help clarify the child's healthcare journey.

Interviews

The aim of the first interview is to gather some information about the child's healthcare journey. We will ask you to describe your involvement in providing burns care to the child. To map the healthcare journey of the child we will ask questions about the processes influencing when and why you provided certain care. For example, we will ask you questions about priorities, health system or service requirements, perceived difficulties in providing care, and what helped in being able to provide good burns care. Any subsequent interviews will follow the same format and focus on care received since the last interview.

Are there any benefits for my participating in the study?

There are no known benefits for you for participation in this study. We hope that the results from this study will better inform treatment of burn injuries to help ensure that all children get the best care available.

Are there any side-effects and risk associated with this study?

There are no physical side-effects or known risks associated with this study. If you feel uncomfortable with any question or become upset during the interviews you don't need to answer those questions or we can stop the interview. We can also organise for you to see a counsellor.

Other information

Participation in this project is voluntary and if you decide not to take part or decide to withdraw at any time this will not affect your employment with the heath service or your relationship with those you work in the burns team.

The information you give us will be completely confidential. All the researchers and study staff, Aboriginal and non-Aboriginal, have signed a “Confidentiality” agreement. This means that they agree not to talk about you or about any information you give us, to anyone outside the research team. Your information will remain confidential except in the case of a legal requirement to pass on personal information to authorised third parties. This requirement is standard and applies to information collected both in research and non-research situations. Such requests to access information are rare; however we have an obligation to inform you of this possibility.

Your data will be kept secure on a computer and only the researchers working on this study will have access to the information you provide. Your identity (name and address) will not be kept with your interview answers and records. A report of the study may be published, but no information that could identify you or the health service where you are employed will be published.

If you have any questions about the conduct of this study, please do not hesitate to discuss them with Rebecca Ivers on 02 9657 0300 or Sarah Fraser on 08 8273 7200.

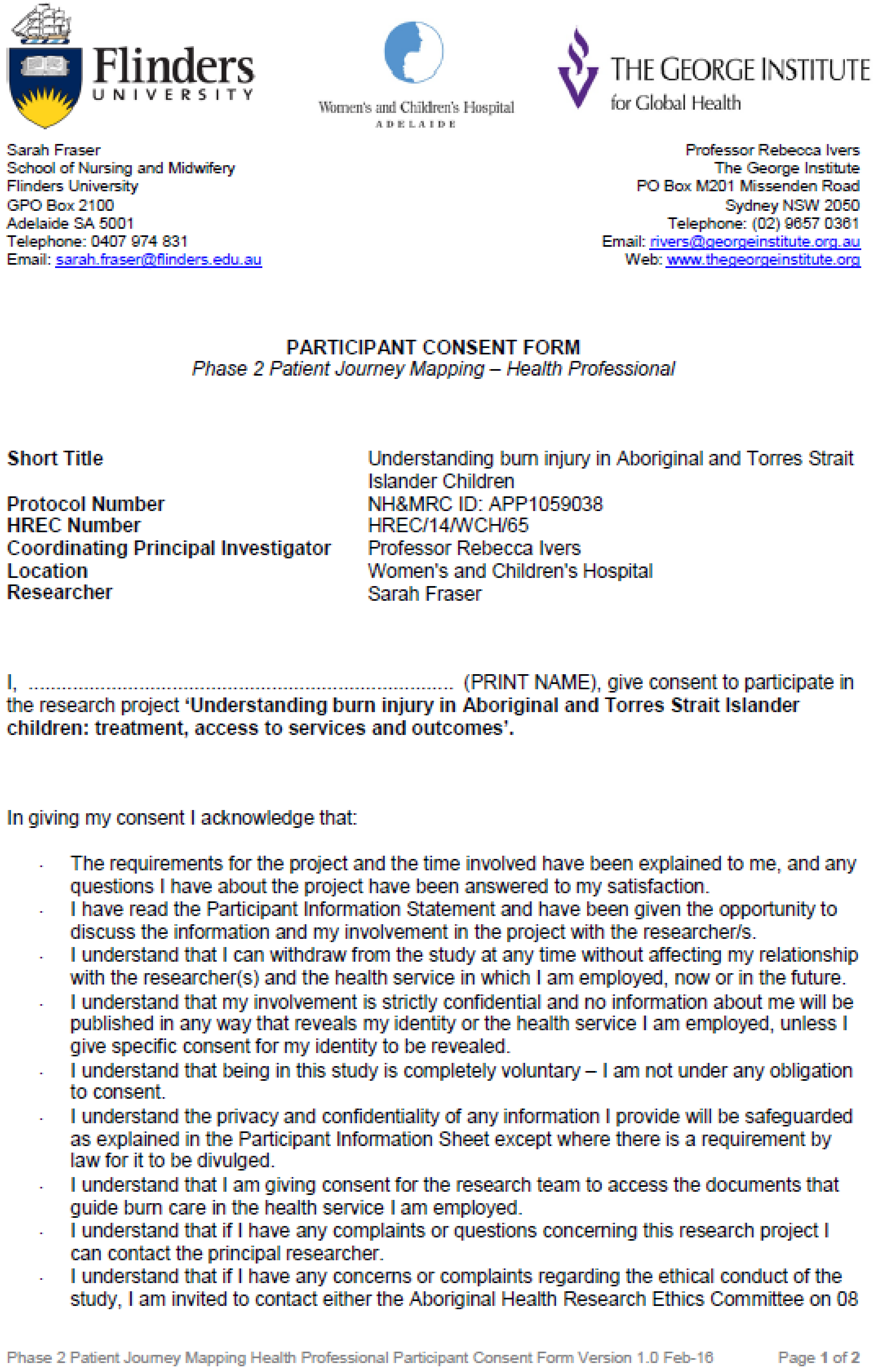
This project has been approved by the Aboriginal Health Research Ethics Committee in your jurisdiction and the Women's and Children's Health Network Human Research Ethics Committee.

If you have any concerns or complaints regarding the ethical conduct of the study, you are invited to contact either the Aboriginal Health Research Ethics Committee on 08 8273 7200 or the Women's and Children's Health Network Human Research Ethics Committee on 08 8161 6521.

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

This research is funded through a National Health and Medical Research Project Grant (APP1059038) and was initiated by Professor Rebecca Ivers at The George Institute for Global Health, The University of Sydney. This research is being co-ordinated by The George Institute for Global Health, The University of Sydney. The researchers for this study are: Professor Rebecca Ivers, Dr Kate Hunter, Ms Julieann Coombes and Mr Jake Byrne (The George Institute for Global Health and the University of Sydney), Dr Serigne Lo (The Melanoma Institute), Professor Andrew Holland (The Children's Hospital at Westmead), Professor Roy Kimble (The University of Queensland) and Dr Kellie Stockton (Royal Children's Hospital), Professor Kathleen Clapham and Dr John Daniels (The University of Wollongong) and Ms Delia Hendrie (Curtin University of Technology), Mr Kurt Towers (Northern and Central Adelaide Local Health Districts), Professor Sandra Eades (Baker IDI), Ms Sarah Fraser, Associate Professor Julian Grant and Dr Tamara Mackean (Flinders University) and Professor Belinda Gabbe (Monash University).

Appendix 18 - Participant consent form for burns team member (research part two)



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PARTICIPANT CONSENT FORM

Phase 2 Patient Journey Mapping – Health Professional

Short Title	Understanding burn injury in Aboriginal and Torres Strait Islander Children
Protocol Number	NH&MRC ID: APP1059038
HREC Number	HREC/14/WCH/65
Coordinating Principal Investigator	Professor Rebecca Ivers
Location	Women's and Children's Hospital
Researcher	Sarah Fraser

I, ... (PRINT NAME), give consent to participate in the research project **'Understanding burn injury in Aboriginal and Torres Strait Islander children: treatment, access to services and outcomes'.**

In giving my consent I acknowledge that:

- The requirements for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
- I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
- I understand that I can withdraw from the study at any time without affecting my relationship with the researcher(s) and the health service in which I am employed, now or in the future.
- I understand that my involvement is strictly confidential and no information about me will be published in any way that reveals my identity or the health service I am employed, unless I give specific consent for my identity to be revealed.
- I understand that being in this study is completely voluntary – I am not under any obligation to consent.
- I understand the privacy and confidentiality of any information I provide will be safeguarded as explained in the Participant Information Sheet except where there is a requirement by law for it to be divulged.
- I understand that I am giving consent for the research team to access the documents that guide burn care in the health service I am employed.
- I understand that if I have any complaints or questions concerning this research project I can contact the principal researcher.
- I understand that if I have any concerns or complaints regarding the ethical conduct of the study, I am invited to contact either the Aboriginal Health Research Ethics Committee on 08

Phase 2 Patient Journey Mapping Health Professional Participant Consent Form Version 1.0 Feb-16 Page **1** of **2**

Appendix 19 - Excel spreadsheet 1, scientific standards and family and healthcare provider perspectives on meeting standards

	The injury (crisis)	Emergency Care (getting help)	Ambulatory Care (out-patient)	Admission (confronting the system)	In-patient care (sustained Interactions)	Discharge (getting home)	Rehabilitation (being home)
ANZBA First Aid Guidelines (http://anzba.org.au/care/first-aid/)	· Stop the burning process. Firstly, consider your own safety. If on fire, stop-drop-roll. If electrical, turn off current. If chemical, remove the burning agent and irrigate with water. Cool the burn. With running cold tap water for 20 minutes. Useful for up to 3 hours after injury. Do not cause hypothermia. Do not use ice. For all burns and scalds. Remove clothing not stuck to the burn site. Remove all jewellery and watches. Cover the burn. Using a clean dressing or cling wrap (do not wrap circumferentially). Seek medical assistance.						
ANZBA Referral Criteria (http://anzba.org.au/care/referral-criteria/)		· Burns greater than 10% Total Body Surface Area (TBSA). Burns greater than 5% TBSA in children. Full Thickness burns greater than 5% TBSA. Burns of Special Areas – Face, Hands, Feet, Genitalia, Perineum, Major Joints and circumferential limb or chest burns. Burns with inhalation injury. Electrical burns. Chemical burns. Burns with pre-existing illness. Burns associated with major trauma. Burns at the extremes of age – young children and the elderly. Burn injury in pregnant women. Non-accidental burns.					
Women's and Children's Hospital Paediatric Burns Service Guidelines (updated 2014)	· Extinguish flame. Remove heat source. Apply 20 minutes cool running water. Remove jewellery and clothing. Continue 20 minutes of running water. Cover with non-adherent dressing. Keep patient warm. (Reference List 1-9).	· Specific Referral Criteria (stated to be based on ANZBA Transfer Guidelines 2012): Any burn where the referring worker requires management or advice from the paediatric burns service; Burns greater than 5–7% TBSA; Burns to face, hands, feet, genitalia,	· For referral to outpatient clinic phone WCH. Infection Control in outpatient setting. Staff attending burns patients in outpatient setting observe standard precautions at all times, including hand hygiene and aseptic non-touch technique and relevant PPE.	· Burn depth assessment and management (Reference List 31-32) « Address psychosocial issues in the acute phase (Reference List 65).	· Psychosocial assessment focussing on the accident causing injury and family member's perceptions around this, past experiences of trauma, family dynamics, cultural and socio-economic factors, barriers to coping and family strengths and supports.	· Psychosocial Issues, prior to discharge. Referral to community agencies for support at home if required. « Patients to receive 'Nutrition for burns' pamphlet prior to discharge (not referenced).	· Psychosocial Issues: Ongoing support with adjustment for family and child. Contribute to cooperation between family and school. Encourage families to access own social supports and appropriate community resources. Visit school with burns team to educate. « Burn

	The injury (crisis)	Emergency Care (getting help)	Ambulatory Care (out-patient)	Admission (confronting the system)	In-patient care (sustained Interactions)	Discharge (getting home)	Rehabilitation (being home)
		perineum, major joints; Full thickness burns; Electrical burns; Chemical burns; Inhalation injury; Circumferential burns; Inpatients with pre-existing medical disorders; Burns with associated trauma; Burn injury with suspicion of non-accidental injury. « Options of digital referral service. For referral contact: burns registrar/on call surgical registrar; burns advanced CPC; burns fellow.			« Pain relief provided from the Department of Children's Anaesthesia provides service and guided by WCH guidelines. « Major burn patients should be assessed within 24 hours of admission by Physiotherapy OR Occupational Therapy (not referenced). « Dietician assessment for burns >10% , <1yo, burn to mouth/hands.		at risk of hypertrophy reviewed and assessed regularly (not referenced). « Healed burns to be moisturised regularly (not referenced). « Scar management tailored to individual patient according to burn site, age, and response to treatment (not referenced).
Government of WA, Department of Health, Injury and Trauma Health Network, PROPOSED Model of Care (2009)	« Provide access to basic online first aid training on burns injury to target the community. « Ensure first aid courses contain burn first aid content.	· Metro clients access tertiary facilities directly, and outer metro/rural/remote require routine links to tertiary facilities. · Transfer protocol should exist and be used between ED and Tertiary Burn Unit. « The facility who has first contact with the burns injury should contact the Tertiary Burn Unit for support and advice. « For minor burns, communication with Burn Unit regardless of confidence in assessment and plan of care. « For moderate burns, communicate with Burn Unit early and adopt recommended guidelines. « Care plan must incorporate rehabilitation throughout all stages of care staring at time of injury. « Laser Doppler technology is used to assess depth. « Access to specialist service is essential and may be off-site, on-site and with e-health. « Initial assessment in ED where staff communicate with state Burn Injury Unit, providing 24-hour turn around service via email images for clinical advice. « Care plan must incorporate rehabilitation throughout all stages of care staring at time of injury.	« An ambulatory burn clinic may provide: Assessment and dressing of minor and non-severe burns, Rehabilitation interventions, Follow-up burn dressing and skin graft management for patients after discharge, Coordination of rehabilitation in the home and, or 'local' therapist input, Long-term scar management and symptom control after discharge, Patient and family teaching and support, Advisory service to other hospitals, health care professionals and community, Patients with a burn who require surgery, with interim burn care until the day of surgery, Ongoing complication risk management and treatment. (p48) « In metropolitan WA, Burn Injury patients have access to outpatient wound care and 'hospital-in-the-home' services that provide all Burn Injury care post inpatient discharge (p48)	« Access to Burn Unit is dependent on post assessment classification of the burns injury using E-health Outreach Service via non-specialist centres for regional/rural/remote (p 35). « Initial assessment informs plan of care which is developed, documented and reviewed on a continual basis. « Laser Doppler technology is used to assess depth. « Specialised rehab input is required upon admission. « Nurses provide holistic care and are integral to patient care from point of admission to rehab to ambulatory care. « Multi-d teams coordinate individual clinical pathways. « Each discipline contributes to treatment plan. « Care plan must incorporate rehabilitation throughout all stages of care staring at time of injury.	« Receive multi-disciplinary inpatient care (p 35). « Care plan must incorporate rehabilitation throughout all stages of care staring at time of injury. « Multi-d teams coordinate individual clinical pathways. « Each discipline contributes to treatment plan. « Care plan must incorporate rehabilitation throughout all stages of care staring at time of injury. « Burn injury team liaises with microbiology and infection control. « The burn injury team works closely with the pharmacist in the management of care. « Nursing staff work closely with other disciplines regarding assessment, delivery and evaluation of patient requirements for pain management. « State-wide e-health service supporting consultant led on-call advisory service. « Patients managed in ICU require coordination of wound care by burn care nurses (p 41) (Reference List 31). « Dietician to assess patient on admission. « Access to pathology services. « Long term access to psychological support and access to psychosocial and/or psychiatric intervention is required. «	« Facilitated early discharge by accessing hospital-in-the-home services, and by using a step down to local non-tertiary hospital for transition to rehabilitation (p 35).	« Care plan must incorporate rehabilitation throughout all stages of care starting at time of injury. « Long term access to psychological support and access to psychosocial and/or psychiatric intervention is required. « Multi-d burns team arranges ambulatory care after discharge from inpatient service. « Ambulatory care team provide link between inpatient and rehab. « Step down facilities are linked to acute services achieve a seamless continuum of care.

	The injury (crisis)	Emergency Care (getting help)	Ambulatory Care (out-patient)	Admission (confronting the system)	In-patient care (sustained Interactions)	Discharge (getting home)	Rehabilitation (being home)
					Access to dedicated clinical psychology role.		
ACI Statewide Burn Injury Service, NSW Burns Transfer Guidelines (2014)	« 20 minutes cool running water within first 3 hours (not referenced).	« Transfer criteria: ANZBA and ISBI. « Appropriate communication and management must be instigated for interstate transfers. « Transfer should occur within four hours if possible (p.14) (not referenced). « Children up to their 16th birthday should be transferred to a children's burn unit (not referenced).					
ACI State-wide Model of Care NSW State-wide Burn Injury Service (2011)	« Not recorded	« Transfer criteria: ANZBA and ISBI. « Use telehealth to support early assessment and management (not referenced).	« provide a seven-day a week ambulatory burn service co-located with acute inpatient burn unit· « consult with a burn surgeon · « accept patients referred from a hospital emergency department, general practitioners, other hospitals, community health services, or self-referred «· burn injury of up to 10% of total body surface area may be managed on an ambulatory basis as appropriate. « Access to · Physiotherapy, · Occupational Therapy, · Social Work, · Speech Pathology, · Nutritional support, · Clinical Psychology « Outpatient community care may include home, school, pre-school and workplace visits. « Referral to dietician if deemed to be at nutritional risk; followed by nutritional assessment allowing for social and cultural needs. Use of step-down facility to allow access to ambulatory care services for rural and remote families.	« Accurate assessment undertaken in the ED in accordance with the admission guidelines with the admission guidelines for individual burn unit (p. 7). « Laser Doppler Imaging to assess depth (Reference List Kim 10, Mill 09). « Emergency surgery within 24 hours post deep circumferential burn (not referenced). « Rehabilitation starts on admission and continues through all stages. The whole patient and family are considered when addressing rehabilitation needs (pg 20). « Based on initial assessment a care plan is developed and documented (not referenced). Case management is commenced on admission (p. 13) (Reference List Curtis 04). « Social work and clinical psychology provide assessment and intervention beginning at admission and continuing (p 17). Social worker undertakes thorough psychosocial assessment to review family history (p 17). « Allied health contributes to all stages of continuum of care guided by clinical practice guidelines (p 15).	« Comprehensive pain management service incorporating a range of modalities and including non-pharmacological and complementary therapies (administered and monitored by Pain Management Service). « Comprehensive nursing care plan developed in consultation with patient and/or caregiver on admission to unit. « Nursing staff provide holistic care. « Multidisciplinary plan of care. « Social work and clinical psychology provide assessment and intervention beginning at admission and continuing (p 17). Social worker undertakes thorough psychosocial assessment to review family history (p 17). « 24 access to operation rooms (p 11). « Peri-operative care of patients requires cross disciplinary planning and organisation of different personnel (p 12). « Burn team maintains close liaison with microbiology and infection control personnel (p 12). « Education teacher on daily basis (p 25). « Paediatric treatment rooms (p 25). « Charity involvement (p 25). « Child protection unit involvement (p 25). « Allied health contributes to all stages	« Pharmacist to provide regular information to child, family, carer on medication at admission and discharge (p 13). « Allied health contributes to all stages of continuum of care guided by clinical practice guidelines (p 15). « Social work and clinical psychology provide assessment and intervention beginning at admission and continuing (p 17). Social worker undertakes thorough psychosocial assessment to review family history (p 17). « Case management for complex cases will continue throughout long-term care to facilitate periodic re-assessment and monitor changes in functionality (p 13) (Reference List Weed 05). « Provide access to sub/acute/step-down facilities.	« Use telehealth for ongoing post-acute care of burn patients (p 8). « Rehabilitation team provides referral to external rehabilitation facilities for on-going management (p 20). « Patients and families continue to receive psychosocial intervention (p 17) and refer to other agencies where required. « Provide access to burns camps for children (Reference List Maslow 10). « Be referred to OT/physio at local services where available with support from burn unit therapists.

	The injury (crisis)	Emergency Care (getting help)	Ambulatory Care (out-patient)	Admission (confronting the system)	In-patient care (sustained Interactions)	Discharge (getting home)	Rehabilitation (being home)
					of continuum of care guided by clinical practice guidelines (p 15).		
Discussions regarding the how points of care/standards were/were not applied							
Caregiver	*So as not to reinforce negative stereotypes, caregiver will not be asked to recall this information. However, if they wish to share the information it will be permitted.*						
Family							
Aboriginal Health Worker							
AHCCHS							
Emergency Care Provider (local hospital, paramedic)							
Surgeon							
Burns Nurse							
Aboriginal Liaison Officer							

	The injury (crisis)	Emergency Care (getting help)	Ambulatory Care (out-patient)	Admission (confronting the system)	In-patient care (sustained Interactions)	Discharge (getting home)	Rehabilitation (being home)
Ngangkari (Traditional Healer)							
Occupational Therapist							
Physiotherapist							

Appendix 20 - Excel spreadsheet 2, Indigenous concepts of health and healing and family and healthcare professional perspectives

	The injury	Emergency care		Admission	Ambulatory care and in-Patient		Discharge and rehabilitation	
Points in time - headings to elicit holistic views of health	**Crisis**	**Getting help**	**Leaving competing obligations**	**Confronting the system**	**Sustained Interactions**	**Being away**	**Going home**	**Confronting competing needs**
Caregiver's perspective	What influenced your ability to provide first aid? Did you have access to running water? Did you have transport to take child to get the care they needed? How easy or difficult was it to get to care? Were there challenges? Were you able to address challenges?	Where and why did you go to get help and did you get the help you needed? How easy or difficult was it to this location? Did you fee able to ask questions and understand what was happening? How did you feel about accessing the health services? Were there challenges? Was there clear communication between staff and between services?	Did the transport support the people in need? Were you able to address any other commitments prior to leaving? What was difficult for you to leave? Are you a carer for other family members? Has the caregiver needed to make arrangements while away? Was transport arranged? Was PATS available?	How did you feel about accessing the health service? Did emergency ask if your child identified as Aboriginal and/or Torres Strait Islander? Could you understand what was happening and being said? Did you fee able to talk and understand what was happening at each stage? Is English your first language? Interpreter? Did you feel safe and respected? Were there challenges? Were you able to address challenges? Did the patient feel able to talk to staff and understand what was happening at each stage? Was communication of concepts and ideas clear, or was confusing medical terminology used?	Were you able to feel comfortable? Were you treated fairly? Were you treated with respect? Did you have specific needs? Were they met? Were there challenges? Was communication of concepts and ideas clear?	What role do you have in the community? Do you have cultural obligations? Has the journey impacted on this? Did you require financial assistance? Could you access money? Were the health services able to assist? What has it cost to be away? Was PATS (transport and accommodation assistance) available? Have any budget or government policy changes impacted (positively or negatively) on the journey? Were there challenges? Were you able to address challenges? Are there particular personal, spiritual, cultural or physical considerations? What are they and how have they impacted this journey? How is the caregiver's physical health generally? Are there any other underlying or new health challenges? What are they and how do they impact?	How did you manage physically getting home? Was assistance available? Was there clear communication between staff and between services?	Were you able to follow suggested discharge plan? Did you understand the discharge plan? Did you have to travel extensively for rehabilitation? Where did the person go to receive care and why? How easy or difficult was it to get to each location?
Child's perspective (6yo or >)	*So as not to recall the trauma of the burns injury incidence, collection of data will not commence until there has been sustained time in the hospital environment.*				Did you feel understood? Did you miss your family, friends, school? What was really good about being in hospital? Was there any health care people that you really liked? What was it that you liked about those people?	Did you feel understood? Was there anything that you missed about being away from home? Did you miss your family, friends, school? Were you able to talk to your family and friends on the phone?	Was it good getting home? What was the best part of being home? Is there anything that your missed about leaving the burns unit at the hospital?	Were you able to attend follow-up care? Did you miss school because of the follow-up care?

	The injury	Emergency care		Admission	Ambulatory care and in-Patient		Discharge and rehabilitation	
Points in time - headings to elicit holistic views of health	**Crisis**	**Getting help**	**Leaving competing obligations**	**Confronting the system**	**Sustained Interactions**	**Being away**	**Going home**	**Confronting competing needs**
Referring Hospital/GP	What was your role in providing health care for this child and family? In regards to systems, what worked well, and what did not?	What was your role in providing health care for this child and family? In regards to systems, what worked well, and what did not?	What was your role in providing health care for this child and family? Did you provide a referral to the burns unit? Was there specific documents that guided your practice? In regards to systems, what worked well, and what did not?	Were you contacted during admission or whilst child was an in-patient?	Were you contacted whilst child was an in-patient?	Did you provide any support to the family in the community whilst the child was away?	Were you contacted prior to the child being discharged and returning home? Did you receive a discharge summary? How did you know the child had returned home?	Were you able to provide the on-going health care needs of the child? Did the child attend the follow-up appointments?
Aboriginal Health Worker	What was your role in providing health care for this child and family? In regards to systems, what worked well, and what did not?	What support were you able to provide to the family? Were you able to provide everything that you thought they needed, or that they wanted?	What support were you able to provide to the family? Were you able to provide everything that you thought they needed, or that they wanted?	Were you contacted during admission or whilst child was an in-patient?	Were you contacted during admission or whilst child was an in-patient?	Were you contacted during admission or whilst child was an in-patient?	Were you contacted prior to the child being discharged and returning home? Did you receive a discharge summary? How did you know the child had returned home?	Were you able to support or provide the on-going health care needs of the child? Did the child attend the follow-up appointments?
Aboriginal Liaison Officer				Was the family referred to you? If not, how did you find out the patient was an inpatient?	Were you able to provide support to the child and family? How? Or if not, why not?	Were you able to provide support to the child and family? How? Or if not, why not?	Were you able to provide support to the child and family in returning home? If so, what support did you provide? Or if not, why not?	Did you provide any support after the child and family had left the burn unit? If yes, what and how?
Ngangkari (Traditional Healer)	What was your role in providing health care for this child and family? In regards to health systems, what worked well, and what did not?	What was your role in providing health care for this child and family? In regards to health systems, what worked well, and what did not?	What was your role in providing health care for this child and family? In regards to health systems, what worked well, and what did not?	What was your role in providing health care for this child and family? In regards to health systems, what worked well, and what did not?	What was your role in providing health care for this child and family? In regards to health systems, what worked well, and what did not?	What was your role in providing health care for this child and family? In regards to health systems, what worked well, and what did not?	What was your role in providing health care for this child and family? In regards to health systems, what worked well, and what did not?	What was your role in providing health care for this child and family? In regards to health systems, what worked well, and what did not?
Burns Nurse		Were you contacted whilst the child received care at the referring health service? If yes, what did you do and in regards to health systems, what worked well, and what did not? Was telehealth used?	Were you aware of the child being transferred and leaving the referring health service to attend the burn unit? If so, how were you notified? What support were you able to provide to the family prior to transfer? Or if not, who was or why not?	When did you first see the child and assess the burn?	How did you ensure that the information you provided to the child and family whilst an in-patient was understood?	Did you provide care to family who attended with the child?	What was your role in supporting the child and family to get home? In regards to systems, what worked well, and what did not? Were you able to provide everything the family needed? How did you ensure follow-up care procedures were understood?	How was the patient followed up? What services were was the family expected to attend? Was the local AHW contacted? Did you provide any follow-up care? If so, how and where? Did you provide a discharge summary and health care plan for another health professional to follow?
Occupational Therapist				Was the family referred to you? If not, how did you find out the patient was an inpatient?	How did you ensure that the information you provided to the child and family whilst an in-patient was understood?	Did you provide care to family who attended with the child?	What was your role in supporting the child and family to get home? In regards to systems, what worked well, and what did not? Were you able to	How was the patient followed up? What services were was the family expected to attend? Was the local AHW contacted? Did you

	The injury	Emergency care		Admission	Ambulatory care and in-Patient		Discharge and rehabilitation	
Points in time - headings to elicit holistic views of health	**Crisis**	**Getting help**	**Leaving competing obligations**	**Confronting the system**	**Sustained Interactions**	**Being away**	**Going home**	**Confronting competing needs**
							provide everything the family needed? How did you ensure follow-up care procedures were understood?	provide any follow-up care? If so, how and where? Did you provide a discharge summary and health care plan for another health professional to follow?
Physiotherapist				Was the family referred to you? If not, how did you find out the patient was an inpatient?	How did you ensure that the information you provided to the child and family whilst an in-patient was understood?	Did you provide care to family who attended with the child?	What was your role in supporting the child and family to get home? In regards to systems, what worked well, and what did not? Were you able to provide everything the family needed? How did you ensure follow-up care procedures were understood?	How was the patient followed up? What services were was the family expected to attend? Was the local AHW contacted? Did you provide any follow-up care? If so, how and where? Did you provide a discharge summary and health care plan for another health professional to follow?
Surgeon		Were you contacted whilst the child received care at the referring health service? If yes, what did you do and in regards to health systems, what worked well, and what did not? Was telehealth used?	Were you aware of the child being transferred and leaving the referring health service to attend the burn unit?	When did you first see the child and assess the burn?	How did you ensure that the information you provided to the child and family whilst an in-patient was understood?	Did you provide care to family who attended with the child?	What was your role in supporting the child and family to get home? In regards to systems, what worked well, and what did not? Were you able to provide everything the family needed? How did you ensure follow-up care procedures were understood?	How was the patient followed up? What services were was the family expected to attend? Was the local AHW contacted? Did you provide any follow-up care? If so, how and where? Did you provide a discharge summary and health care plan for another health professional to follow?
Psychologist				Was the family referred to you? If not, how did you find out the patient was an inpatient?	How did you ensure that the information you provided to the child and family whilst an in-patient was understood?	Did you provide care to family who attended with the child?	What was your role in supporting the child and family to get home? In regards to systems, what worked well, and what did not? Were you able to provide everything the family needed? How did you ensure follow-up care procedures were understood?	How was the patient followed up? What services were was the family expected to attend? Was the local AHW contacted? Did you provide any follow-up care? If so, how and where? Did you provide a discharge summary and health care plan for another health professional to follow?

	The injury	Emergency care		Admission	Ambulatory care and in-Patient		Discharge and rehabilitation	
Points in time - headings to elicit holistic views of health	**Crisis**	**Getting help**	**Leaving competing obligations**	**Confronting the system**	**Sustained Interactions**	**Being away**	**Going home**	**Confronting competing needs**
Social Worker				Was the family referred to you? If not, how did you find out the patient was an inpatient?	How did you ensure that the information you provided to the child and family whilst an in-patient was understood?	Did you provide care to family who attended with the child?	What was your role in supporting the child and family to get home? In regards to systems, what worked well, and what did not? Were you able to provide everything the family needed? How did you ensure follow-up care procedures were understood?	How was the patient followed up? What services were was the family expected to attend? Was the local AHW contacted? Did you provide any follow-up care? If so, how and where? Did you provide a discharge summary and health care plan for another health professional to follow?

Data collection may be through semi-structured interviews and medical record review. Medical record reviews will facilitation recall for some participants.

Appendix 21 - PJM tool Spreadsheet One. Scientific standards and family and healthcare providers meeting standards.

Burn care standards [30-32, 34, 35]	The injury	Emergency care	Ambulatory care	Admission	In-patient care	Discharge	Rehabilitation
Standards achieved by healthcare service and healthcare professionals	· 20 minutes cool running water within first 3 hours · Remove jewellery and clothing · Cover with non-adherent dressing · Seek medical assistance · Keep warm · Provide access to basic online first aid training on burn injury to target the community · Ensure first aid courses contain burn first aid content		· Burns greater than 5% in children · Full Thickness burns greater than 5% · Burns of special areas · Burns in very young · Children up to their 16th birthday should be transferred to a children's burn unit · Metro clients access tertiary facilities directly, and outer regions require routine links to tertiary facilities · Access to specialist service	· Consult with a burn surgeon · Access to physiotherapy, · occupational therapy, social work, speech pathology, nutritional support, clinical psychology · Ambulatory burn clinic provides assessment and dressing of minor and non-severe burns, rehabilitation interventions, follow-up burn dressing and skin graft management for patients after discharge · long-term scar management and symptom control · patient and family teaching and support · ongoing complication risk management and treatment · advisory service to other hospitals, healthcare professionals and community	· Social worker undertakes thorough psychosocial assessment to review family history and address psychosocial issues in the acute phase · Accurate assessment undertaken in the ED in accordance with the admission guidelines for individual burn unit · Laser Doppler Imaging to assess depth · Rehabilitation starts on admission and whole patient and family are considered when addressing rehabilitation needs · Care plan is developed and documented and reviewed on a continual basis . Case management is commenced on admission · Allied health contributes to all stages of continuum of care guided by clinical practice guidelines · Nurses provide holistic care and are integral to patient care from point of admission to rehabilitation to ambulatory care · Multi-disciplinary teams coordinate individual clinical pathways · Each discipline contributes to treatment plan	· Social work and clinical psychology provide assessment and intervention · Dietician assessment for burns >10%, <1yo, burn to mouth/hands · Nursing staff work closely with comprehensive pain management service incorporating a range of modalities and including non-pharmacological and complementary therapies · Care plan incorporates rehabilitation throughout all stages of care starting at time of injury and family are considered when addressing rehabilitation needs · Major burn patients should be assessed within 24 hours of admission by physiotherapy OR occupational therapy · Multidisciplinary plan of care · Allied health contributes to all stages of continuum of care guided by clinical practice guidelines · Multi-disciplinary teams coordinate individual clinical pathways · Receive multi-disciplinary inpatient care · Each discipline contributes to treatment plan · Burn injury team liaises with microbiology and infection control · The burn injury team works closely with the pharmacist in the management of care	· Pharmacist to provide regular information to child, family, carer on medication at admission and discharge · Allied health contributes to all stages of continuum of care guided by clinical practice guidelines · Social work and clinical psychology provide assessment and intervention · Address psychosocial issues, prior to discharge . Case management for complex cases continues throughout long-term care to facilitate periodic re-assessment and monitor changes in functionality · Patients to receive 'Nutrition for burns' pamphlet prior to discharge

Burn care standards [30-32, 34, 35]	The injury	Emergency care	Ambulatory care	Admission	In-patient care	Discharge	Rehabilitation
						· State-wide e-health service supporting consultant-led on-call advisory service · Patients managed in ICU require coordination of wound care by burn care nurses · Access to pathology services · Nursing staff provide holistic care · 24 hour access to operation rooms · Paediatric treatment rooms · Child protection unit involvement	
Standards not achieved by healthcare service and healthcare professionals			· Provide 7day/week ambulatory burn service co-located with acute inpatient burn unit · Burn injury patients have access to 'hospital-in-the-home' services post inpatient discharge	· Clinical psychology provides assessment and intervention at admission	· Comprehensive nursing care plan developed in consultation with patient and/or caregiver on admission to unit	· Facilitated early discharge by accessing 'hospital-in-the-home' services, and by using a step down to local non-tertiary hospital for transition to rehabilitation	· Use telehealth for ongoing post-acute care of burn patients · Rehabilitation team provides referral to external rehabilitation facilities for ongoing management · Be referred to OT/physio at local services where available, with support from burn unit therapists · Patients and families continue to receive psychosocial intervention and refer to other agencies where required.
Standards not applicable for this burn care journey		· Inhalation, electrical, circumferential and chemical burns · Burns with illness · Burns with major trauma · Any burn where the referring worker requires management or advice from the paediatric burn service · Burn injury with suspicion of non-accidental injury · Appropriate communication and management instigated for interstate transfers within 4 hours · The facility who has first contact with the burn injury	· accept patients referred from a hospital emergency department, general practitioners, other hospitals, community health services, or self-referred · burn injury of up to 10% of total body surface area may be managed on an ambulatory basis · Outpatient community care may include home, school, pre-school and workplace visits · Referral to dietician if deemed to be at nutritional risk; followed by nutritional	· Emergency surgery within 24 hours post-deep circumferential burn · Access to Burn Unit is dependent on post-assessment classification of the burn injury using E-health Outreach Service via non-specialist centres for regional/rural/remote	· Education teacher on daily basis · Psychosocial assessment focussing on the accident causing injury and family member's perceptions around this, past experiences of trauma, family dynamics, cultural and socio-economic factors, barriers to coping and family strengths and supports. · Long term access to psychological support	· Provide access to sub/acute/step-down facilities · Referral to community agencies for support at home if required	

Burn care standards [30-32, 34, 35]	**The injury**	**Emergency care**	**Ambulatory care**	**Admission**	**In-patient care**	**Discharge**	**Rehabilitation**
		contacts the unit for support and advice · For minor burns, communication with unit regardless of confidence in assessment and plan of care · For moderate burn, communicate with unit early and adopt recommended guidelines · Laser Doppler technology is used to assess depth · Initial assessment in ED where staff communicate with state unit, providing 24-hour turnaround service via email images for clinical advice	assessment for social and cultural needs · Use of step-down facility to allow access to ambulatory care services for rural and remote families · patients with a burn who require surgery, with interim burn care until the day of surgery				
Standards unable to be assessed			· Staff attending burn patients in outpatient setting observe standard precautions at all times, including hand hygiene and aseptic non-touch technique and relevant PPE				· Step-down facilities are linked to acute services to achieve a seamless continuum of care · Provide access to burn camps for children · Contribute to cooperation between family and school · Visit school with burn team to educate
Data from Case Notes and discussions (where able) regarding how standards were/were not applied							
Caregiver	Had completed first aid training		Accessed emergency ambulance care	Travelled in private car to appointments. From daily dressing to once every 6 weeks.	Time in emergency department then transferred to ICU.	Four days in ICU (and staying at home at nights) and four weeks in surgical unit (staying at home and sometimes in hospital).	Travelled home in private car. Felt hurried out and inadequately prepared to provide necessary at-home care.
Family	N/A		Contacted by phone after accident occurred	Travelled in private care with caregiver occasionally	Arrived at hospital after admission to ICU	Visited often in private car	
Aboriginal Health Worker (AHW)	No AHW employed		No AHW employed	No AHW employed	No AHW employed	No AHW employed	No AHW employed
ACCHS	Not accessed by the family		Not utilised by the family	Not accessed by the family	Not utilised by the family	Not utilised by the family	Not utilised by the family
Emergency Care Provider	Not able to contact place of injury or those present at time of injury		Not able to contact Ambulance worker Case Notes: Mandatory notifications made	N/A	N/A	N/A	N/A
Surgeon	N/A		N/A	Consults as necessary	Surgical assessment within 4 hours of admission to hospital	Surgical intervention	Discharge note made
Burn Nurse	N/A		N/A	Arranged care appointments and supported caregiver in	Support transition to ICU and then to ward. In regular	Developed initial care plan. Led case conferences with medical staff. Involved	Gave information regarding required care.

Burn care standards [30-32, 34, 35]	The injury	Emergency care	Ambulatory care	Admission	In-patient care	Discharge	Rehabilitation
				minimising time spent in hospital	contact with caregiver and giving constant information.	multidisciplinary team. Reviewed at least daily.	Arranged follow-up appointments
A/ILO	N/A			No support provision	Not notified	On A/ILO list. Seen and offered support. Did not attend case conferences.	Seen prior to discharge and support offered
Traditional Healer	N/A		No traditional healer employed	No traditional healer employed	No traditional healer employed	No traditional healer employed	No traditional healer employed
Occupational Therapist	N/A		N/A	Consults in scar clinic	Assessed within 8 hours of admission	In patient care provided. Attended case conference. Input into care plan.	Discharge note made
Physiotherapist	N/A		N/A	Consults in scar clinic	Assessed within 24 hours of admission	In patient care provided. Attended case conference. Input into care plan.	Discharge note made
Psychologist	N/A		No input into care. Not able to be contacted.	No input into care. Not able to be contacted.	No input into care. Not able to be contacted.	No input into care. Not able to be contacted.	No input into care. Not able to be contacted.
Social Worker	N/A		Attended ED. Supported, engaged and explained.	No input into care.	Able to provide support to caregiver and available for all level 1 trauma.	Provided initial assessment of caregiver, supported, engaged and provided intervention where necessary and supported access to fuel and food vouchers. Attended case conference.	Discharge note made

Appendix 22 - Emden’s core story analysis, Kate and Ava’s story

A mother, Kate, her toddler son, Tom and baby Ava attended a planned appointment concerning Tom. During the appointment, Ava became hungry and restless and Kate organised for her bottle to be heated. Ava suffered an accidental serious scald injury. Kate’s instincts were to pull Ava from the child’s restraint in which she was laying. Instructed by staff to take Ava to the shower for first aid, Kate removed Ava’s clothes. As Kate removed Ava’s clothes, she saw the *‘blistering and her skin just going down the drain’*. She felt like ‘the worst person in the whole world’ and was unsure of what to do.

On-site staff had phoned triple zero for emergency care and were arranging for the care of Tom with family contacts from Kate’s phone. Kate was hysterical and staff removed other people in close vicinity from the area. When the ambulance arrived, paramedics wrapped Ava in glad-wrap and they asked Kate if she was going to come to the hospital with them. They also asked if Ava was Aboriginal and/or Torres Strait Islander. Kate said yes to both. There was a police officer in attendance in the Ambulance en-route to the tertiary children’s hospital.

On arrival at the hospital, Ava was taken in to the resuscitation room. The emergency response team was in attendance and *‘it was so crazy in that room’*, Kate said. Emergency team staff said to Kate: *‘we’re going to put you over in this corner so you can stay with her but you can’t be in the way’*. Kate was asked Ava’s weight and said she *‘couldn’t even hear her [Ava]. There wasn’t crying, wasn’t anything, [she] didn’t even know at that stage if she [Ava] was even alive, like, [she] couldn’t see her, couldn’t hear her’*. *‘I wanted to know what was going on but I couldn’t get those answers and then the only people at that stage that were talking to me was a police officer and a social worker’*. The lead emergency doctor introduced themselves to Kate and said Ava was in good hands. The social worker, police officer and doctors kept asking Kate questions. *‘Everyone [was] just asking me [Kate] all these questions and I [Kate] had to keep saying the same thing over again, again’*. Kate was asked once by staff if Ava was Aboriginal and/or Torres Strait Islander. The social worker was a great support to Kate, was the best source of information, and made Kate feel as comfortable as possible.

Once Ava was stable, she was transferred to the PICU and Kate, who was still in wet clothes from the shower, was given warm blankets. Kate’s parents arrived at the hospital and Kate retold the story to them. While Ava was receiving treatment in PICU, Kate and her family sat outside *‘in the family room and just [were] waiting and waiting and waiting’*. After what seemed like an eternity to Kate and her family, a PICU doctor finally came out and said that Ava was stable. The doctor also assessed Kate’s burns, which were superficial and did not require any medical intervention. Kate was provided access to a shower and some scrubs to change into. She was desperate to talk to her husband, Ava’s father, who was uncontactable. Kate and her parents felt left out and did not know what was happening with Ava during the first few hours of treatment. Kate’s mother *said ‘…to be left in the dark like that – would have been nice if we had someone come in to say, look, there’s been a few problems, you know, but you don’t know’.*

After some time, another doctor came out to given an update on Ava’s condition. This time Kate was invited into the PICU to be with Ava but was told: *‘you won’t be able to see her again for the rest of the day so, sort of, appreciate – appreciate it’*. Kate felt like they were taking Ava away and that she wouldn’t be allowed to see her again, ever. Kate’s mother went in with her for support. They weren’t allowed to touch Ava and had to wear gloves, a mask and a gown.

It was the hardest thing for Kate to hear that she was not allowed to touch her baby in the time of most need. Kate’s mother was in shock at the sight of Ava. The heat in Ava’s room was unbearable.

After visiting Ava for a short time, Kate’s parents took Kate home to see her son, Tom. On arriving at her husband’s parents’ home, who had collected Tom from the place of injury, Kate held Tom and cried. Kate was very surprised to learn from her in-laws that *‘all while we were at the hospital, low and behold to me, ah, there was an investigation happening’*. She had thought it was strange when the police officer at the hospital had told her that ‘it’s okay. It’s been classed as an accident. I’m going’. Kate was so worried and felt she had been left in the dark. This was an assessment regarding child abuse and she *‘feared they were going to take Ava and Tom away’*. Kate’s in-laws told Kate her car was unable to be taken from the place of injury due to the police investigation. The car was released a few hours after the incident. Kate never collected the clothes Ava was wearing on that day.

Ava stayed in the PICU for five nights. Day two was hard for Kate and her parents. This was when the severity of Ava’s burns became overtly evident. *‘Overhearing staff talk about the severity [of Ava’s condition] was the worst’.* Kate’s mother and father supported Kate during these early days and provided care for Tom. The family travelled at least one hour to and from the hospital each day as there was only one PICU parent’s room and that was occupied. Kate arranged for weekly car parking to reduce the cost of casual parking.

During Ava’s stay in the PICU, communication regarding Ava’s condition and care from staff got better and better. Kate felt continuity of staff was very helpful and in general, *‘the nurses explained a lot’*. Sometimes however, inconsistency of messages made Ava’s time in PICU somewhat confusing for Kate and her family. Nonetheless, the staff also made sure Ava was safe and that only family who were allowed to see her, came in. After Kate and her family left at night to go home, Kate would phone to see how Ava was.

> *'The PICU nursing staff would tell me everything over the phone. I would say that I want every update that's happened since I left. I want to know if there are any doctors' notes and I want everything. It was really good. We felt very comfortable and it helped me go to sleep'.*

Ava was moved from the PICU to the surgical ward in the hospital on day six of her admission. The main burns nurse, Lucy organised for Kate and her family to be introduced to the surgical ward nurses prior to moving. Kate was asked by a staff member of the surgical ward if Ava was Aboriginal and/or Torres Strait Islander. Lucy met with Kate frequently, especially in the early days of Ava's admission and supported Kate in holding Ava for the first time since the injury. Kate said, *'I literally cried, I was so happy to be able to finally hold her'.*

Tom would visit Ava daily with Kate unless it was a day care day. However, it was not until Ava had been in hospital for a few days that Kate became aware that there was a child's crèche available. This would have been helpful to know earlier as Tom was not allowed in the PICU for very long at any given time. Over the next four weeks Kate started using the crèche for Tom, however Tom became very clingy and needed to sleep in Kate's bed at night. He also became angry and would throw a lot of tantrums. Family support was very important in terms of helping with Tom, especially as he became increasingly challenging. Tom wanted Kate and *'when I [Kate] was there, I [she] wasn't really emotionally there'*.

Over the following weeks, Kate arranged her life around being with Ava in the hospital. She stayed at home at night during the weekdays, and overnight in the hospital with Ava on the weekends. Kate also drove several hours once a week to visit her husband. Tom would mostly accompany Kate on these visits, however he stayed with Kate's parents as necessary. Kate described every day to be like *'ground-hog day'*.

Kate experienced extreme financial stress for the period of Ava's time in hospital. Kate *'had no idea how I would get through'*. She would sacrifice bills and would pay only what was most necessary and leave what she could not pay. At the time of the injury, Kate had been planning on returning to work to support herself and her two children. This never happened. Meals at the hospital were expensive, and there was very little suitable food for children. Sometimes Kate's parents would pay for the meals, which cost hundreds of dollars if they were there seven times in a week. Kate would also try and pack her lunch to reduce costs. The social worker organised fuel vouchers. This was almost $200 over the four weeks. Kate was also supported with 14 meal vouchers. Kate's application for the carer's pension with Centrelink was declined as she was deemed not eligible because Ava was too young and expected that she already be in 24-hour care.

Ava had multiple surgeries that Kate was required to give consent for. Kate said that *'for her first lot of skin grafts they actually sat in there and answered every single question we had, no matter how stupid it was'.* Many of the times following the initial consent, medical staff would seek verbal consent over the phone for the surgical procedures given Kate lived so far away and could not be there in person all of the time. Kate would go to the hospital after the surgery and be there when Ava came out. There was nothing Kate felt she didn't understand in the consenting process and the process got quicker for every surgery Ava had. *'I'm putting my absolute trust in you that, like, yes, I want to know what you're doing but at the same time I'm not going to go sit there looking for a better solution because that's going to delay her care'*.

On one occasion, there was confusion and the nurse was rude to Kate over the phone. *'…I've treated them with the utmost respect and courtesy, everything, and then just if they – being spoken to like that on the phone it was, like, that's not on…I deserve some respect'.* Kate reported this to the lead burns nurse, Lucy the next day. There was also one night when nursing staff would not give information about Ava over the phone, even though it had been given every other night. Sometimes Kate felt it was difficult to get messages left for staff on the next shift. Especially about expected visitors. This was the result of a communication breakdown between staff. Again, Kate reported these things to Lucy who rectified the communication problems. Mostly though, Kate was happy with the communication and care from staff.

Not only did Kate feel consistently guilty about Ava's injury, she was often made to feel guilty about not coming in to be with Ava. However, when she did come in, she was told off when Tom or her nieces and nephews were being too loud. She also often felt judged by healthcare professionals in the cafeteria when her extended family were visiting. *'You could tell from the vibe from some of the other doctors and stuff when you're in the cafeteria, like, you're being loud and you're this and you're that and, like, I'm trying, you know'*.

For a long time, the nurses provided all care for Ava, and Kate thought it was mostly nice to have their support. However, when Ava moved to care that was not one on one, Kate was expected to do everything for Ava, without having been taught how. Kate said that *'no-one actually sat there and taught us how, they just thought we knew'*. Kate was disappointed by this.

After four long weeks, Kate was ecstatic to be leaving the hospital and going home with Ava. She was told to take everything from the room to care for the wounds as it would only be thrown out. Kate was given very quick instructions on how to change Ava's dressings on the morning she left the hospital. She left the hospital feeling immensely apprehensive about having Ava at home and having to do the wound care all by herself. This was made better by the communication with hospital clinical staff upon being home. This was especially true regarding the care of Ava's dressings. Kate was very disappointed to learn in the discharge summary upon being home that Ava had been resuscitated twice in the PICU and she had not been told.

Outpatient appointments at the hospital after discharge meant getting up very early, with Tom staying at Kate's parents' house the night before so as not to have to wake him at 6.00am. The appointments were almost three hours long with one hour's drive each side of the appointment. They started as twice a week, then moved to once per week, then fortnightly, then every three weeks, every four weeks and then every six weeks. Ava would get very upset and restless during the long outpatient appointments.

Access to Close the Gap helped Kate with the cost of medications and bandages post-discharge. Kate was not sure she would have been able to afford all of these extra products if it had not been for this scheme. Kate continues to worry about the rising costs of care for Ava over her long-term care journey. Kate has also had to purchase new things to keep Ava protected from the sun, such as special swimwear. Kate's parents keep their own stock of cream to care for Ava at their home. The creams and wash are expensive, and all of the family have struggled with these costs. With Kate's return to work, the financial stress has decreased somewhat. The cost of Ava's special garments is extraordinary, and Kate was thankful she did not need to pay for these. She would not have been able to afford them.

While Kate was thrilled to be home, the nights were difficult, especially when Ava's wounds were itchy. It was sometimes very difficult for her to get to sleep. For Kate, taking the silicone off herself was difficult because it made her think she was ripping the skin off. This reminded her of the time of the injury. Although Kate had the support of the social worker while in hospital, this worker's obligations stopped as soon as we left the hospital. Kate was offered a psychologist once Ava was discharged from the hospital to work with. Kate continues to be concerned about Ava showing signs of post-traumatic stress disorder.

Ava continues to get better. For the moment, outpatient appointments are six-weekly, and Ava has started laser treatment for her scars. Kate continues to successfully manage Ava's care with Tom, work and other commitments.

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