Understanding Burn Injuries in Aboriginal and Torres Strait Islander Children
Acknowledgement of Country

The authors would like to acknowledge the Traditional Custodians of the land upon which the report was written. We pay our respect to all Elders past, present and emerging and recognise that our Elders are the knowledge holders of our lands, waterways and communities.

Artist

Artwork by Kylie Cassidy, a Wiradjuri woman.

Contents

2  The Coolamon Study
3  What is a Coolamon?
4  What did we do?
   Sub-studies
5  What did we learn?
7  What’s next?
8  Conclusions and recommendations
   Participating sites
   The Team
9  Publications
Despite the significant burden of burn injury, to date there has been no work that examines care received or its impact on outcomes in Aboriginal and Torres Strait Islander children, or has sought to hear directly from Aboriginal and Torres Strait Islander families about their experiences of burn related health care.

What is a Coolamon?

Coolamon were primarily used by Aboriginal and Torres Strait Islander women to carry tools, babies, food and, depending on its shape, even water. Another use of the Coolamon was for digging. In dryer areas, collected seed were tossed in the air from the Coolamon to allow the wind to blow away the husks.

Our research to understanding burn care for Aboriginal and Torres Strait Islander Children was named the ‘Coolamon Study’ and uses a pictorial representation of a Coolamon as it was used by Aboriginal mothers for generations to hold and protect their children just as families whose child has sustained a burn injury hold and protect their child today.

The Coolamon study explored the care of Aboriginal and Torres Strait Islander children with burns through a mixed methods study conducted in New South Wales, the Northern Territory, Queensland and South Australia. We talked to children and their families about the impact and cost of burns, to understand their experiences and to find better ways of caring for children with burn injuries.

**Our mission is to change the life trajectories of Aboriginal and Torres Strait Islander children who experience a severe burn injury and access healthcare.**

We aim to transform burn care via our research so that it is more equitable and accessible to Aboriginal and Torres Strait Islander families across Australia. Working with Community, focusing on health care systems, healthcare professionals, economics, and most importantly, family experiences, the research from the Coolamon Study will result in changes that impact on those children and families requiring access to burn healthcare into the future.

Aboriginal and Torres Strait Islander health means “not just the physical well-being of the individual but the social, emotional, and cultural well-being of the whole community. This is a whole-of-life view and it also includes the cyclical concept of life-death-life.”


Why the Coolamon Study?

Burns in children can be devastating and traumatic injuries causing life-long scarring, severe psychological trauma and loss of function across multiple domains. Aboriginal and Torres Strait Islander children experience burns at least twice the rate of other children and are less likely to be treated in a hospital with a paediatric burns unit, despite needing more intensive treatment and a longer stay.

There are well documented barriers to accessing safe and high-quality tertiary and primary healthcare for Aboriginal and Torres Strait Islander people in both urban and rural/remote settings. Having consistent access to high quality care is fundamental to good outcomes in burn care. Aboriginal and Torres Strait Islander Community-Controlled Health Services continue to provide excellent and cost-effective care for their communities. However, the cultural safety that is found in such services is not always seen in provision of care in hospitals.
What did we do?

- We’ve heard the stories, interviewed and yared with about 205 parents and families
- We’ve talked to more than 80 clinicians
- We have reviewed burn data over a decade (over 4000 children)
- We’ve reviewed Models of Care for burns from around the world

Sub-studies

As part of the Coolamon study four women have completed doctoral degrees (PhD), exploring aspects of burn injury and care for Aboriginal and Torres Strait Islander children across Australia in four sub-studies:

- A disjuncture of world views: manifestation in burns care for Aboriginal and Torres Strait Islander children in Australia - Sarah Fraser
- Is anybody listening? Stories from Australia’s First Nations Families whose Children had Sustained a Burn Injury - Julieann Coombes
- Discovering the Interwoven Health Inequities in Aboriginal and Torres Strait Islander Children with an Acute Burns Injury - Courtney Ryder
- Fire and smoke: The social and emotional impact of paediatric burn injuries and care on Aboriginal and Torres Strait Islander families - Hayley Williams

What did we learn?

About burn inequities:

- Inequities in injury burden are greatest in children from low socio-economic status backgrounds and those who experience longer hospital length of stay (LOS).
- A minority of Aboriginal and Torres Strait Islander children are getting gold standard burn first aid and access to emergency care.
- Aboriginal and Torres Strait Islander children have a hospital length of stay 4 days longer than other Australian children for acute burns. Remoteness, flame burns, percentage total body surface area are contributing factors. These health inequities, low socio-economic status and Streptococcus sp. infection are greater in Aboriginal and Torres Strait Islander children than other Australian children.
- The manifestation of inequities creates additional burden through Out-of-Pocket Healthcare Expenditure (OOPHE) on Aboriginal and Torres Strait Islander families. Travel, accommodation and medication are all OOPHE costs impacting families for their child’s burn treatment.
- Reduced functional and health related quality of life levels pre-injury or baseline, longer hospitalisation, and lower socioeconomic status were linked to poorer long-term outcomes.
- Paediatric burn injuries and care cause a broad range of severe social and emotional burdens for all members of Aboriginal and Torres Strait Islander families, several of which remain prevalent throughout the entirety of burn care and last months to years following the burn event.

In these sub-studies, the research focused on:

- Exploring the health system and healthcare professional aspects of burn care. Specifically to explore what guides burn care, how burn care is delivered and structured, and if it meets the needs of this population.
- Hearing the stories of families, including documenting the barriers and facilitators to aftercare, and if they contribute to poor health outcomes, and to better understand what appropriate resources are needed to support families leaving the tertiary health system and improve access to burn aftercare.
- Using Indigenous research methodologies to provide a detailed examination of how health inequities impact on Aboriginal and Torres Strait Islander children with an acute burn injury in big data and survey psychometrics.
- Using participant observations, thinking aloud, and yarning methods to explore the social and emotional impact of paediatric burn injuries and care on Aboriginal and Torres Strait Islander families, their unmet support needs, their parenting strengths during burn care, and factors that contributed to their resilience.
Regarding burn care:

- Existing models of care for burn injuries do not meet all aspects of quality or cultural safety.
- There is a disconnect between Western and Indigenous knowledges; this is manifest in both Australia’s mainstream healthcare system and in the documents that inform burn care.
- Burn 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.
- Equity in healthcare is limited with restricted capacity for the delivery of care based on needs other than those aligned with the biomedical model.
- Multiple issues exist related to equity and equality in the delivery of burn care for Aboriginal and Torres Strait Islander children.
- Families’ experiences in burn aftercare within health services in Australia comprised of significant barriers in accessing healthcare following their child’s burn.
- Racism, distance to aftercare services, cost of transport and parking in hospital grounds for outpatient clinics and disconnection from family were some barriers that families voiced as central issues. However, there were also some clear facilitators such as the support of First Nations Health Workers and Liaison Officers.
- Racism, stereotyping, judgement, and stigmatization were prevalent throughout acute burn care and greatly contributed to Aboriginal and Torres Strait Islander families’ poorer social and emotional wellbeing and extreme fear of the Department of Child Safety involvement.
- There is inadequate access to mental health specialists and support services to assist families’ coping during acute burn care and recovery beyond care.
- Poor referral pathways to existing support services, including mental health specialists and Liaison Officers, greatly contributes to families’ isolation and experiences of severe social and emotional burdens.
- Burn health professionals’ providing quality care that is culturally responsive, trauma informed, and collaborative is key to determining if Aboriginal and Torres Strait Islander families thrive during burn care or experience additional burdens.
- Aboriginal and Torres Strait Islander caregivers’ engaged approach to parenting is an asset to acute burn care processes; however, requires greater support from burns health professionals to be effectively integrated into care practices.
- It is fundamental for First Nations families to have input into care received and clear and concise communication on the care that is needed for ongoing burn aftercare to be effective.
- Most barriers can be alleviated by First Nations Health Workers’ support and involvement in the child’s burn aftercare.

What’s next?

The Coolamon Study has led to the development of several new pieces of research that will improve burn care for Aboriginal and Torres Strait Islander people.

A new burn model of care in NSW

Led by Siobhan Connolly at the Agency for Clinical Innovation (and PhD candidate at UNSW) this work will involve working with consumers and clinicians to co-design a new statewide model of care (MOC) that incorporates findings from the Coolamon Study. The development of the MOC is commencing in 2022.

Safe Pathways

This project has been informed by families whose child had sustained a burn injury. The development of a culturally appropriate model of care for Aboriginal and Torres Strait Islander children who have been in hospital with a burn injury is being delivered at The Children’s Hospital, Westmead. An Aboriginal Health Worker will support the child and family once they have been admitted to the burn services as an inpatient or an outpatient. The Aboriginal Health Worker will also connect families with local primary healthcare in the family’s community and specialist burn services to ensure effective, culturally appropriate ongoing burn care. The project outcomes are quality improvement and system effectiveness. The discharge plan will minimise missed appointments ensuring a clear pathway for the child’s aftercare needs leading to an easy transition from the burns unit to appropriate burn aftercare achieving optimal healing.

Building Cultural Safety and Capabilities (BCC)

The BCC training program has been developed by Aboriginal Senior Researchers and Health Workers working at The Children’s Hospital at Westmead in the burn services with topics that focus on improving the understanding of Aboriginal and Torres Strait Islander Health within a cultural safety framework and in the context of history, society, culture and Aboriginal and Torres Strait Islander models of health. The BCC is imbedded into the Safe Pathways project to improve cultural healthcare for Aboriginal and Torres Strait Islander families whose child is hospitalised in a burn unit.

Community co-ordinated burn care

All NSW Aboriginal Community Controlled Health Services will be invited to participate in a culturally safe integrated model of burn care. Each participating service will nominate Aboriginal Health Care workers and clinicians to receive burn training delivered by the NSW State-wide Burn Injury Service (SBIS). Each service will receive funding support to cover personnel costs and/or resources. Burn education experts will work alongside ACCHS to tailor the education program to meet the service’s needs, ensuring alignment of best practice burn education with relevance to the local services. The CHW Burn Unit will work with the newly created network to coordinate ongoing burn care for Aboriginal and Torres Strait Islander children. This will ensure provision of and access to culturally responsive burn care and will remove existing barriers to ongoing burn care such as travel, separation from family and time away from work for carers and school for children.
Conclusions and recommendations

The Coolamon Study has addressed many issues in burn care for Aboriginal and Torres Strait Islander children. Through our research we have a better understanding of the factors that lead to better care, and those that can be harmful, including inequitable and sometimes discriminatory treatment. Institutionalised racism in the health system is something that must be addressed with systems level responses.

There is a clear need for patient-centered and trauma informed care that explicitly addresses the needs of Aboriginal and Torres Strait Islander people through a whole-of-family approach. This includes provision of culturally safe care, including better training of clinicians, and resourcing of Aboriginal and Torres Strait Islander Health Workers, as well as development of resources specifically for Aboriginal and Torres Strait Islander people. This also includes better social and emotional wellbeing support for Aboriginal and Torres Strait Islander families through collaborative involvement in care, adequate social and emotional wellbeing screening, access to a mental health specialist at all times, and efficient referrals to mental health specialists, First Nations Health Workers, and Liaison Officers. As we found, many barriers can be alleviated by First Nations Health Workers’ support and involvement in the child’s burn aftercare but systems level policies that ensure quality care for all are also essential.

Participating sites

- The Royal Darwin Hospital, Northern Territory: https://nt.gov.au/wellbeing/hospitals-health-services/royal-darwin-hospital
- The Women’s and Children’s Hospital, South Australia: www.wch.sa.gov.au/
- The Queensland Children’s Hospital, Queensland: www.childrens.health.qld.gov.au/qch/
- Townsville Hospital and Health Service, Queensland: www.townsville.health.qld.gov.au/

The Team

Lead Investigators
Prof Rebecca Ivers, Prof Kathleen Clapham, A/Prof Tamara Mackean, Prof Andrew Holland, Prof Roy Kimble, Dr Kate Hunter, Dr Bronwyn Griffin, Mr Anthony Spann, Mr Kurt Towers, Serigne Lo, A/Prof Delia Hendrie, A/Prof Warwick Teague, Prof Julian Grant, Anne Darton, Dr Harry Stalwski, Prof Sandra Eades, Dr Bernard Carney, Linda Quinn, Tom Potokar.

PhD Graduates
Dr Julianne Coombes, Dr Sarah Fraser, Dr Courtney Ryder, Dr Hayley Williams

Committees
The Aboriginal and Torres Strait Islander Advisory Committee met quarterly to provide overall guidance and advice for the Coolamon Study. This included ensuring appropriate Aboriginal involvement at all levels and promoting the opportunity for Aboriginal community engagement. Members of the advisory committee include parents of patients and clinicians, as well as Aboriginal investigators and PhD students involved in the Study.

Publications
