







BMJ Open Codesigning informative resources for families of Aboriginal and Torres Strait Islander children who sustained a burn injury: a protocol for a participatory action research study

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ABSTRACT

Introduction Parents of children hospitalised in a burn unit experience psychological trauma and later post-traumatic stress. Aboriginal and Torres Strait Islander families whose child has been admitted to a burn unit encounter additional burdens through a culturally unsafe healthcare system. Psychosocial interventions can help reduce anxiety, distress and trauma among children and parents. There remains a lack of interventions or resources that reflect Aboriginal and Torres Strait Islander people's perspective of health. The objective of this study is to codevelop a culturally appropriate informative resource to assist Aboriginal and Torres Strait Islander parents whose child has been hospitalised in a burn unit.

Methods In this participatory research study, the development of a culturally safe resource will build on Aboriginal and Torres Strait Islander families' experiences and voices, complemented by the knowledge and expertise of an Aboriginal Health Worker (AHW) and burn care experts. Data will be collected through recorded yarning sessions with families whose child has been admitted to a burn unit, the AHW and burn care experts. Audiotapes will be transcribed and data will be analysed thematically. Analysis of yarning sessions and resource development will follow a cyclical approach.

Ethics and dissemination This study has been approved by the Aboriginal Health and Medical Research Council (AH&MRC) (1690/20) and the Sydney Children's Hospitals Network ethics committee (2020/ETH02103). Findings will be reported to all participants and will be disseminated with the broader community, the funding body and health workers at the hospital. Dissemination with the academic community will be through peer-reviewed publications and presentations in relevant conferences.

INTRODUCTION

Burn injuries are one of the most severe forms of injury, usually requiring painful treatment.¹ Compared with adults, children are at increased risk of experiencing

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Empowerment of Aboriginal and Torres Strait Islander families through a participatory action research approach.
- ⇒ Implementation of a cyclical approach to data analysis and resource development to ensure Aboriginal and Torres Strait Islander voices are not lost during data interpretation.
- ⇒ Research decolonisation through the use of indigenous knowledge and indigenous research methods to produce new knowledge that is empowering rather than deficit based.
- ⇒ The cultural contexts of participating families could be different to other Aboriginal and Torres Strait Islander communities, which may affect generalisability.

burn injuries, which can result in long-term consequences, including scarring, deformity, disability and chronic pain.^{2,3} Many children with deep dermal burns require treatment in hospital.⁴ Parents, carers and extended family of children who sustain a burn injury experience significant stress from witnessing a potentially life-changing injury, guilt in relation to responsibility for the injury and trauma through participating in their child's painful medical procedures and worrying about the impact of the burn on the child's future.⁵⁻⁸ Parents of children with burn injuries experience higher psychological distress than parents of children with other types of injuries and medical conditions.⁹ Parents of children hospitalised for burns injuries experience anxiety, depression and post-traumatic stress disorder (PTSD) for up to 7 years after the injury.^{6,10,11}

In young children, the capacity of emotion regulation is highly dependent on their parent's emotional responses.¹² Parents play an essential role in protection and comfort of a child's feelings and emotions and learning how to scaffold and organise their reactions and coping strategies.¹³ If a parent is experiencing a decreased capacity to provide this attachment, through emotional distress or PTSD, poorer recovery and post-traumatic stress symptoms (PTSS) in children can ensue.^{13 14} Furthermore, parental psychological distress affects parenting quality and has been associated with poor health, development and behavioural problems in school.^{15 16} Parental post-traumatic stress and depression are associated with suboptimal overall child recovery from injury.¹⁷

In Australia, Aboriginal and Torres Strait Islander children have more than double the risk of being hospitalised for a burn injury, longer hospital length of stay and a greater mortality rate than other Australian children.^{18 19} This highlights inequities and additional burden that Aboriginal and Torres Strait Islander parents face. It is well documented that Aboriginal and Torres Strait Islander people often experience intimidation, racism and discrimination in the Australian healthcare system, which is further exasperated by a Western Biomedical model of health,^{20–22} lack of culturally safe healthcare services^{20 23} and a system not cognisant of the cultural determinants of health and well-being.^{20 24 25} To add further to this disenfranchisement, ongoing colonisation and systematic racism adds to the trauma burden with the majority of Aboriginal and Torres Strait Islander families fearing child protection service engagement.^{24 26 27}

Provision of clear and detailed information about the child's medical condition, hospital environment, planned medical procedures and coping strategies are recognised in the literature as important components of psychosocial interventions to support parents of hospitalised children cope with depression and anxiety and reduce PTSS/PTSD.^{28–31} Parents whose child has sustained a burn injury report desire clear information on their child's current status and the road ahead to help relieve feelings of fear, frustration and uncertainty.³² Past research has shown that families receiving written information about the department's procedures, report feeling calmer and prepared for what to expect.³² In addition, clearly written information and instructions about planned medical procedures also help parents and children prepare which reduces anxiety and uncertainty.³³ Despite evidence on psychosocial interventions including educational resources to reduce anxiety, distress and trauma among caregivers of hospitalised Australian children, a recent systematic review (17 studies) did not find interventions reflecting Aboriginal and Torres Strait Islander people's perspectives of health.³⁴

The objective of this study is to codesign a culturally appropriate informative resource to assist Aboriginal and Torres Strait Islander parents and carers whose child is hospitalised in a burn unit. More specifically, this study will aim to answer the following questions:

1. What information should be included in a resource to support Aboriginal and Torres Strait Islander families/carers of children admitted to a burn unit during hospital stay?
2. What format would be best to deliver the information?

METHODS

Our research is underpinned by participatory action research (PAR) methodology and research at the knowledge interface.

Participatory action research

PAR is a research methodology which focuses and engages on enabling action by the community of research focus.^{35 36} PAR reflects and questions the source of knowledge used in research and whom it ultimately benefits.³⁶ In this sense, PAR values and privileges the knowledge systems of the community of research interest and advocates for equitable power relationships between the researcher and the community fostering empowerment and research ownership.^{35 36} Because PAR enables communities to define the problem based on their own experiences and knowledge and actively participate in the decision-making process to solve it, it is a methodology that is welcoming of indigenous research paradigms and research agendas.³⁵ Being a PAR that aims to benefit Aboriginal and Torres Strait Islander families, this study will build on families' knowledge and experiences and will incorporate indigenous research methods (see below yarning and data analysis) that enable prioritising Aboriginal and Torres Strait Islander voices and health and well-being paradigms. For the conduct of this study, the authors aim to move away from the deficit discourse that has characterised Aboriginal and Torres Strait Islander research.³⁷ We aim to conduct a study underpinned by Aboriginal and Torres Strait Islander leadership that results on benefits defined by the community itself.

Research at the knowledge interface

Throughout this study, the research team will work at the interface between science and indigenous knowledge described by Mason Durie.³⁸ 'Research at the interface' is an Indigenous research methodology, which allows indigenous and western systems of knowledge to come together to conduct research practice. Within the research interface, western scientific knowledge systems or worldviews and indigenous knowledge systems work together in equal partnership to generate new approaches that translate into benefits for First Nations Peoples and communities.^{38–41} When working at the research interface, Durie lists four main principles that must underline practice⁴²:

1. Mutual respect which entails a recognition of validity and respect for both systems, their spaces and the meaning interpretations arising from different worldviews.
2. Shared benefits by recognising indigenous peoples as active participants in the research process and ensuring

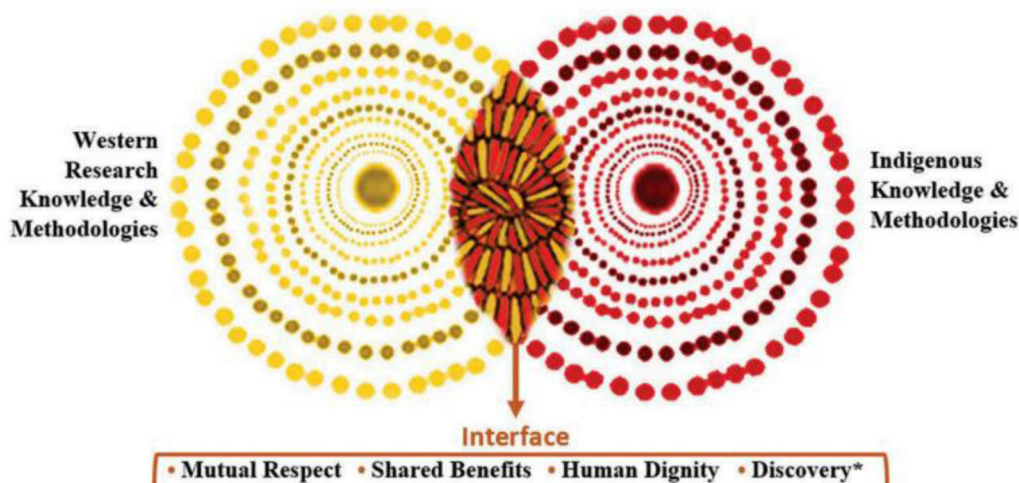


Figure 1 Visual representation of the Interface between science and Indigenous Knowledge as depicted by Ryder *et al.*³⁹

ing communities where research is undertaken are directly benefitted from the research.

3. Human dignity implying that personal integrity and cultural identity are not devalued or dismissed despite cultural and worldview clashes.
4. Discovery which refers to collaborative exploration and invention between both systems to move together beyond outcomes that could have only been achieved from either system alone.

Ryder *et al* have visually represented the research interface as two different species of plant fibres (indigenous knowledge systems and western scientific knowledge systems) that are weaved together in the same way Aboriginal and Torres Strait Islander peoples traditionally created coiled baskets³⁹ (figure 1). Besides providing the coiled baskets analogy, Ryder's research work is an example of conducting research at the interface. The author used quantitative analyses to describe paediatric burn injuries in Australia, including a stratified comparison across Aboriginal and Torres Strait Islander children and other Australian children. This was complemented through Indigenous research methods such as collaborative yarning and Yuri Ingarninthii (deep listening surrounding 'recording and understanding') to unpack and understand the outcomes from the statistical analysis. By integrating both system knowledges, Ryder's work yielded quantitative measures of data analysis that evidenced disparities in burn-related health outcomes for Aboriginal and Torres Strait Islander children while evidencing deeper inequities that shape those outcomes in the context of a colonised country.⁴³

Indigenous research methods

Aboriginal and Torres Strait Islander communities across Australia have maintained stories, dance and songlines pertaining to meteorology, astronomy, medicine, natural resource management, physics and chemistry for over 60 thousand years.⁴⁴ Despite centuries of cultural genocide and denial of indigenous knowledge as a legitimate

knowledge system by European colonialism, indigenous knowledges have endured and continued to develop. In addition, First Nations peoples are decolonising research by reclaiming their sovereign right to their own identities, definitions, intellectual and cultural property.^{45 46}

Yarning

Yarning describes the process of communication between Aboriginal people sharing stories and/or information.⁴⁷ Within this way of conversation, participants build an accountable relationship and engage in an informal and relaxed discussion about topics of interest.⁴⁷ Yarning is increasingly used as an indigenous research method to collect data in a way that is culturally safe for Aboriginal and Torres Strait Islander participants.^{25 48 49} Because yarning occurs in a relaxed and opened manner, it facilitates in-depth discussion providing a source of rich data on a particular subject.⁴⁷ Throughout this study yarning will be used as the method to collect data.

Setting

The Clubbe Ward based at the CHW is the paediatric arm of the New South Wales (NSW) Statewide Burn Injury Service. CHW is the referral unit for all major paediatric burn in NSW, also caring for major plastic surgery and general surgical patients.⁵⁰ This study is part of a broader project called 'Safe Pathways', which is being delivered at the Clubbe Ward with the aim of ensuring culturally safe and ongoing burn care for Aboriginal and Torres Strait Islander children and their families. Safe Pathways includes the delivery of a culturally safe discharge planning service provided to families by an Aboriginal Health Worker (AHW) and the delivery of a Building Cultural Safety and Capabilities training programme for health workers in the burn services of the hospital. The current study sits within Safe Pathways by codeveloping a tool (the resource) to support Aboriginal and Torres Strait Islander families and facilitate the delivery of culturally safe and family-centred care.

Participants

Aboriginal and Torres Strait Islander families whose child, aged 0–16 years, is hospitalised at the Clubbe Ward, an AHW, a mental health expert and health-care providers (members of the multidisciplinary burn team) at the Clubbe Ward, together with Aboriginal and non-Aboriginal researchers from the Guunu-maana (Heal) Aboriginal and Torres Strait Islander Health Program at the George Institute for Global Health, will be partners in the codesign of the resource.

A sample of Aboriginal and Torres Strait Islander families will be approached and invited to participate in the study by a member of the research team. Their cultural knowledge (which includes health and well-being

paradigms) and experience having a child hospitalised at the burn unit, will guide the development of the resource. We aim to recruit approximately 10 families.

An Aboriginal Research Associate from Guunu-maana (Heal), the Aboriginal and Torres Strait Islander Health program at The George Institute for Global Health will invite all potential participants to participate. The researcher will be introduced to families in the Clubbe Ward by the AHW working there. The researcher will go through the participant information sheet and all potential participants will have the opportunity to discuss their potential involvement prior to consenting to participate. A consent form will be signed by the participant and a time that suits them will be decided on for data collection. Ideally,

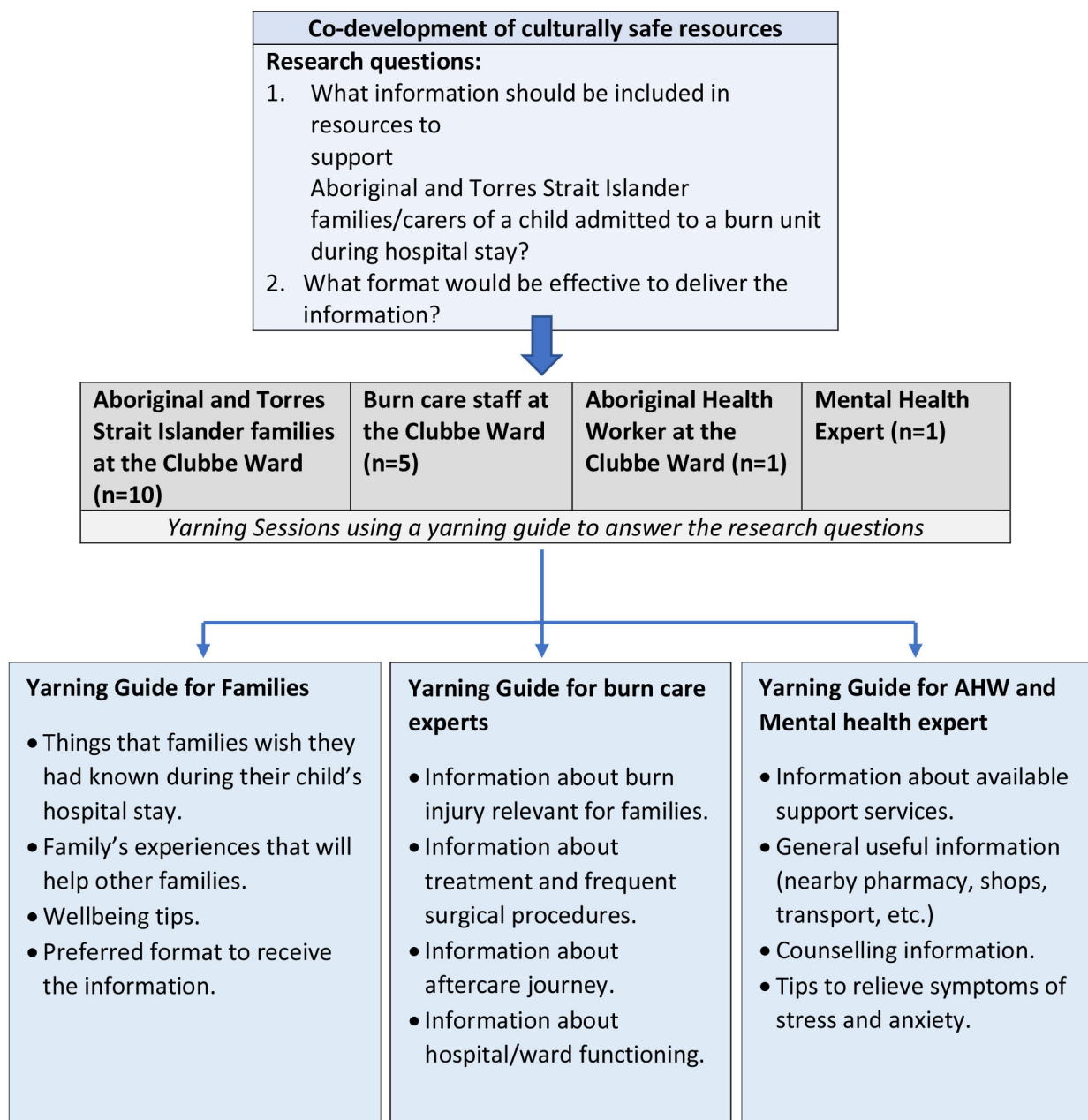


Figure 2 Data collection.

yarning will be conducted in person, but could also be conducted online should that be required due to COVID-19 or other restrictions.

An AHW with extensive experience supporting Aboriginal and Torres Strait Islander families will be invited to participate. The AHW has been employed to specifically support families of Aboriginal and Torres Strait Islander children admitted to the Clubbe Ward and, therefore, has knowledge and experience of the specific needs of families whose child has sustained a burn injury. A mental health expert will be also invited to participate. The mental health expert will be able to share strategies to reduce stress symptoms such as breathing techniques that could be explained in the resource to help parents alleviate stress symptoms. To ensure alignment with Aboriginal and Torres Strait Islander health paradigms and values, the mental health expert will be either an Aboriginal or Torres Strait Islander person. In partnership with the Clubbe ward manager, five healthcare practitioners will also be invited to participate ensuring a spread of members from the multidisciplinary team.

Data collection

Data will be collected through separate yarning sessions with Aboriginal and Torres Strait Islander families, burn unit staff, a mental health expert and the AHW (figure 2). The yarning sessions will be conducted by author CK using a yarning guide previously developed by the research team to facilitate collection of relevant data (see figure 2).

We aim to recruit families of 10 children and yarn with at least one parent or primary carer of each child. However, respecting the value of extended family for Aboriginal and Torres Strait Islander people, more than one parent or family member will also be able to participate in the yarning session according to each family's wishes. One-on-one yarning sessions with healthcare practitioners at the burn unit, the mental health expert and the AHW will be conducted with the aim of collecting information from the viewpoint of multiple experts.⁵¹ Only one yarning session will be conducted with each health expert. The yarning sessions will last no longer than 45 min.

The objective of this study will be to design resources that are culturally safe and relevant, reflecting Aboriginal



Figure 3 Data analysis with a cyclical approach. Adapted with permission from 'Is Anybody Listening? Stories from Australia's First Nations Families whose Children had Sustained a Burn Injury' by J. Coombes⁵³ (p28).

and Torres Strait Islander health paradigms and prioritising Aboriginal and Torres Strait Islander voices.

Specific content and form the resource will take will be guided by the data collected to answer the research questions. We anticipate that the resource will include shared families' voices and stories, information about the healing process, coping with isolation and aimed at facilitating a more efficient transition into other connected systems (eg, accommodation, financial assistance and psychological support).

Data analysis and resource codevelopment

All yarning sessions will be recorded and transcribed verbatim to facilitate data analysis. Transcripts will be imported to NVivo (QSR International, Doncaster, Australia) to facilitate qualitative data analysis, which will be conducted following an inductive thematic analysis approach.⁵²

It is imperative to ensure that the voices of Aboriginal and Torres Strait Islander people are reflected. For this reason, the analysis process of the data from the yarning

sessions with the Aboriginal and Torres Strait Islander participants will follow a cyclical approach⁵³ (figure 3). Each transcript of the yarning session will be sent to the participant who owns the data. The researcher will contact the participant after they have had a chance to read their transcripts and a collaborative process of yarning together with the researcher will present the opportunity to review and amend or add any information, they think is relevant. After these steps, the researcher will proceed to conduct the inductive thematic analysis. The resulting themes will be sent one more time to Aboriginal and Torres Strait Islander participants to ensure Aboriginal and Torres Strait Islander voices are not altered by the researcher's interpretation of the data.

Once Aboriginal and Torres Strait Islander participants have approved the themes that emerged from their transcripts, these will be used with the themes emerging from the yarning sessions with the rest of the participants to guide the resource development. An iterative approach to development of the resources will occur. Drafts of the

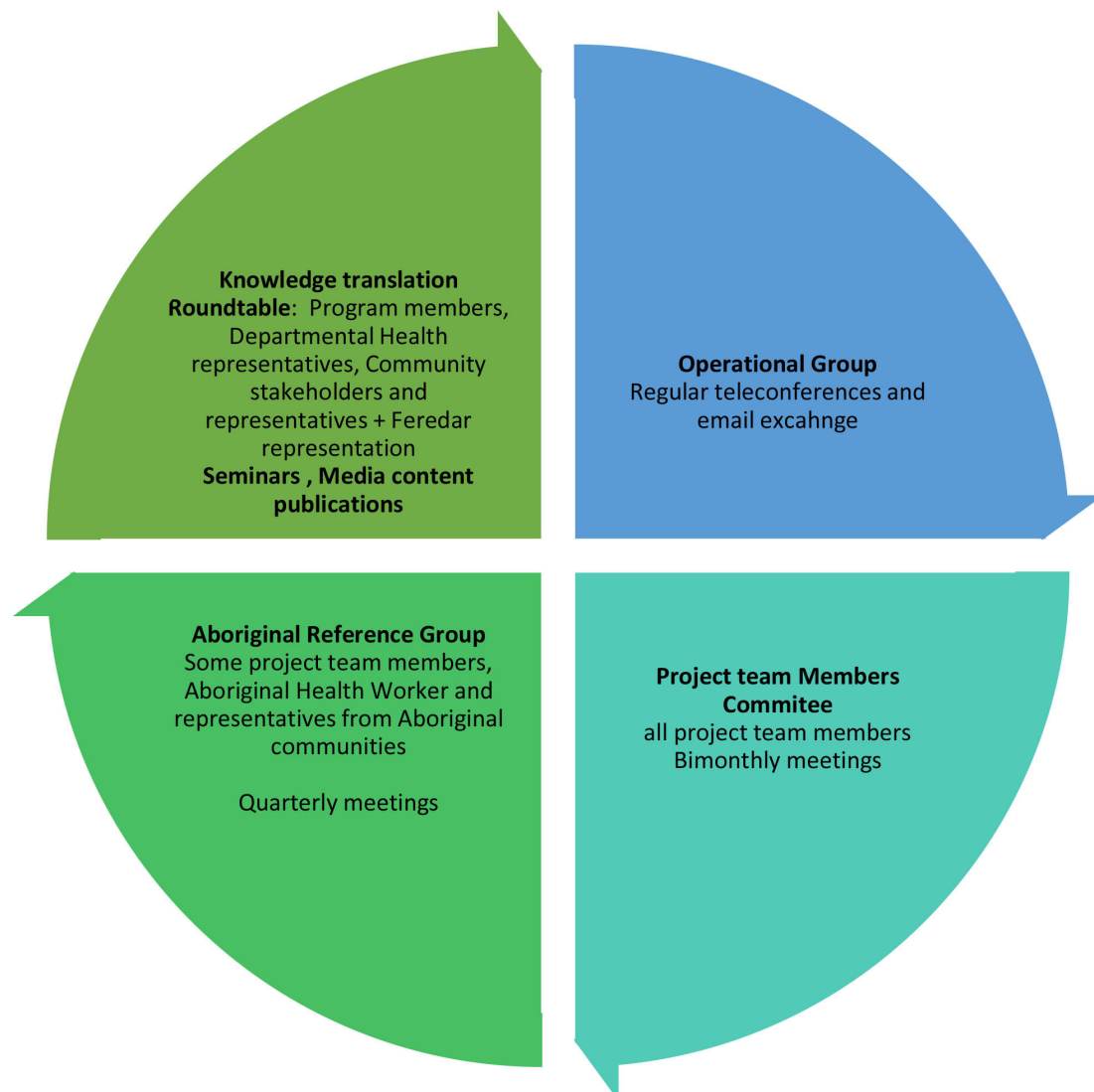


Figure 4 Safe Pathways Study governance.

resources will be sent to all participants (Aboriginal and Torres Strait Islander and non-Indigenous) as part of the resource development process. All participants will have the opportunity to provide feedback and participate in the codevelopment process.

Feedback during the resource development process will also be sought from the Aboriginal Reference Group, which has been engaged to oversee all research activities under the Safe Pathways project (see the Governance section). The resource is aimed at supporting Aboriginal and Torres Strait Islander families in a way that acknowledges and respects Aboriginal ways of knowing (including health paradigms), being and doing. For this reason, during the resource development process, priority will be given to the wishes expressed by families. Medical expert guidance from healthcare practitioners will be used to support and complement the information on topics that families wish to see in the resource.

Governance

The study is led by Aboriginal, Torres Strait Islander and non-Indigenous researchers at Guunu-Maana (Heal), The Aboriginal and Torres Strait Islander Health Program at The George Institute for Global Health. Guunu-Maana has internal policies in place to ensure that research conducted is underpinned by equity, transparency and self-determination. Guunu-maana is committed to maintaining an Aboriginal and Torres Strait Islander paradigm of health and healing integrating physical, emotional, social, cultural and spiritual elements of health.

In addition, this study will be overseen by an Aboriginal Reference Group comprising Aboriginal and Torres Strait Islander community members, representatives of Aboriginal Organisations and representatives from NSW Health. As this study is part of the overarching study Safe Pathways, its governance will follow the same study oversight structure (figure 4).

Patient and public involvement

The design of this study has been reviewed by the Aboriginal Reference Group, which includes Aboriginal and Torres Strait Islander community members. The yarning guide will be approved by the Aboriginal Reference Group before data collection. Findings will be shared with the Aboriginal Reference Group and will be disseminated with the broader community through Aboriginal Community Controlled Health Organisations.

Ethics

This study has been approved by the Aboriginal Health and Medical Research Council (AH&MRC) reference number 1690/20 and the Sydney Children's Hospitals Network ethics committee 2020/ETH02103. The guidelines from the Australian Institute of Aboriginal and Torres Strait Islander Studies for ethical research in Indigenous studies⁵⁴ and the guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research^{55 55} will be followed.

Dissemination

Findings from this study will be fed-back to the participants during the multiple phases of resource development. In addition, findings will be disseminated to the broader community through the Aboriginal Reference Group and Aboriginal Community Controlled Health Organisations. Findings will also be disseminated with the academic community through publication in scientific journals and presentations in relevant conferences, symposia and meetings.

Expected outcomes and significance

Through this study, healthcare experts and researchers from a Western Biomedical model, Aboriginal and Torres Strait Islander researchers and community members will work together to improve healthcare delivery. Each participant will contribute with their own expertise to create a piece of work that builds on the experience and voices of Aboriginal and Torres Strait Islander families whose child is hospitalised with a burn injury. These knowledge, experiences and voices will support other Aboriginal and Torres Strait Islander families who may go through the same process. The final resource will have the potential to be modified in the future to support Aboriginal and Torres Strait Islander adults and children hospitalised with other medical conditions and their families.

In addition to the study's main output (the resource), this study will raise the voice of Aboriginal and Torres Strait Islander families to increase the understanding of the challenges and needs experienced during a child's hospitalisation. Findings from this study can inform further strategies to support Aboriginal and Torres Strait Islander families navigate the Healthcare system through their child's healthcare journey. Findings will also contribute to national efforts to build a healthcare system that is inclusive of Aboriginal and Torres Strait Islander health and well-being paradigms and is experienced as culturally safe by all Aboriginal and Torres Strait Islander peoples.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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