

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

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

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For numbered affiliations see end of article.

Correspondence to

Professor Rebecca Ivers;
rivers@george.org.au

ABSTRACT

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

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

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

Strengths and limitations of this study

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

INTRODUCTION

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

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

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 care¹⁰ 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 study¹² 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 Question¹⁷ 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 Survey¹⁸ 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†	POSAS†	POSAS†
		Hospital Medical Records Data‡	Hospital Medical Records Data‡	Hospital Medical Record Data‡

*HRQOL: Health-related quality of life collected via PedsQL.²⁰

†POSAS: Patient and Observer Scar Assessment Scale.²³

‡Hospital Medical Record Data. Injury: context, prehospital care, including transfers and specific events. Patient's social history, medical history, details of multidisciplinary care, dressings and intensive care admissions. Procedures for theatre and additional burn assessment notes.

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

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

Medicare linkage

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

Qualitative research

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

Patient and family perspectives

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

and reflections of the complexity of care experienced²⁶ 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 commodity²⁸ dissociated from cultural meanings.²⁹ Particular care will be taken during interviews to ensure that the data remain connected to the larger moral community²⁸ 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 enablers 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 `optmix` 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.

Author affiliations

¹Injury Division, The George Institute for Global Health, University of Sydney, Sydney, New South Wales, Australia

²School of Midwifery and Nursing, Flinders University, Adelaide, South Australia, Australia

³Poche Centre for Indigenous Health, University of Sydney, Sydney, New South Wales, Australia

⁴Australian Health Services Research Institute, University of Wollongong, Wollongong, New South Wales, Australia

⁵Department of Epidemiology and Preventive Medicine, Monash University, Melbourne, Victoria, Australia

⁶School of Public Health, Curtin University, Bentley, Western Australia, Australia

⁷National Critical Care & Trauma Response Centre, Royal Darwin Hospital, Darwin, Northern Territory, Australia

⁸Australian Centre for Children's Burns and Trauma Research, University of Queensland, Brisbane, Queensland, Australia

⁹Paediatric Burn Unit, Women's and Children's Hospital, Adelaide, South Australia, Australia

¹⁰Aboriginal Health, Northern and Central Adelaide Local Health Networks, Adelaide, South Australia, Australia

¹¹Department of Burns & Plastic Surgery, Welsh Centre for Burns & Plastic Surgery, Swansea, UK

¹²Poche Centre for Indigenous Health and Wellbeing, Flinders University, Adelaide, South Australia, Australia

¹³Farr Institute, Swansea University Medical School, Wales, UK

¹⁴Faculty of Medicine, University of Sydney, Sydney, New South Wales, Australia

¹⁵Department of Aboriginal Health, Baker IDI Heart and Diabetes Institute, Melbourne, Victoria, Australia

¹⁶Discipline of Paediatrics and Child Health, The Children's Hospital at Westmead, Sydney, New South Wales, Australia

Twitter Follow Rebecca Ivers at @rebeccaivers

Contributors All authors were involved in conception of (RI, AJAH, KH, KC, RK, DR, AS, SL, BG, TP, KT, RAL, DH, SE, JD) or refining (KS, RS, LQ, JC, SF, TM, JG, LJ) of the study protocol. RI and LJ wrote the first draft of the manuscript; all authors contributed to editing and revisions of subsequent drafts.

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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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