

Challenges and lessons learnt implementing longitudinal studies of Aboriginal and Torres Strait Islander children and young people: A qualitative study

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Abstract

Purpose Scant attention has been paid to the experiences of researchers engaged in cohort studies of minority populations such as Indigenous children and their families. This qualitative study aimed to explore the practical challenges, strategies and solutions used by researchers representing 10 prospective cohort studies of Australian Aboriginal and Torres Strait Islander children and young people.

Methods Eighteen researchers, 44.5% of whom identified as Aboriginal, were interviewed. Reflexive thematic analysis was conducted.

Main findings Four overarching themes were generated from the dataset: (1) getting things just right; (2) build and nurture connections with community and staff; (3) 'sit and yarn with them': approaches to recruitment and retention; and (4) great responsibility. These themes underline the importance of developing early community partnerships to guide the scope and direction of the research, building a solid team of local Aboriginal researchers with community connections, and prioritising two-way learning and feedback loops from the beginning.

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Principal conclusions It is imperative to take a flexible and pragmatic approach to longitudinal studies involving Aboriginal children and their families that minimises participant burden while respecting local needs and priorities. Lessons learnt will be useful to new researchers undertaking, or planning to undertake, longitudinal research with First Nations populations.

Keywords: Aboriginal and Torres Strait Islander; Indigenous; Child health; Longitudinal studies; Retention; Follow-up

Highlights

- Aboriginal and Torres Strait Islander leadership and governance from the outset is essential to guide the scope and direction of research.
- Research must be aligned with community values and priorities.
- Only collect what is necessary – avoid scope creep.
- Be flexible and do not put extra burden on families.
- Lack of time and funding are major barriers to developing, implementing and disseminating meaningful research with Aboriginal and Torres Strait Islander communities.

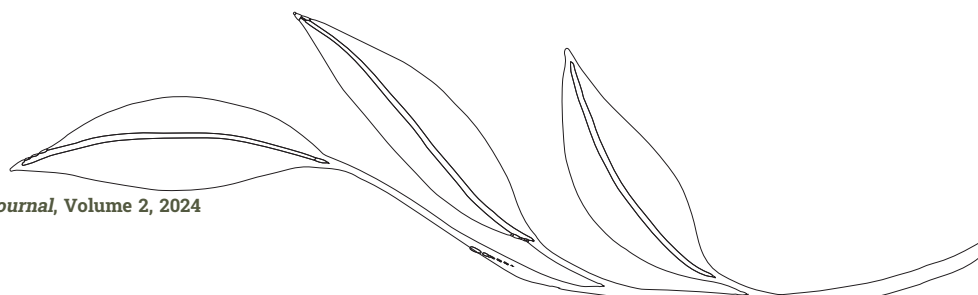
Introduction

Longitudinal cohort studies provide valuable insights into associations between various risk factors and health outcomes in a specific group of individuals over time. Longitudinal data can help unravel the complex interplay between social, behavioural, cultural, economic, environmental and biological factors influencing health and wellbeing (Caruana et al., 2015). Cohort studies starting in pregnancy, at birth or in early childhood are well placed to identify critical windows of susceptibility and opportunities to intervene (Canova & Cantarutti, 2020). Findings can have significant impacts on policymaking, healthcare interventions and overall understanding of human development and behaviour.

Conducting cohort studies is a complex and time-consuming endeavour that requires substantial resources. Several factors must be carefully considered, including funding, personnel, infrastructure, timelines, data collection methods,

recruitment and retention approaches. These practical considerations play a key role in determining whether the study can realistically be conducted as designed and provide reliable results. There is a wealth of literature providing guidance on these issues (Vasconcelos et al., 2019; Teague et al., 2018; Booker et al., 2011; Young et al., 2007; Cotter et al., 2005; Hunt & White, 1998). However, few articles cover the additional processes that are required to ensure that research including Aboriginal and Torres Strait Islander children and their families is meaningful, ethical and beneficial. Editorial limitations often preclude detailed explanations of this important additional work, with some notable exceptions (Maple-Brown et al., 2020; Thurber et al., 2018; Wright et al., 2016; Lawrance et al., 2014; Buckskin et al., 2013; Rae et al., 2013; Dodson et al., 2012; Comino et al., 2010; Knight et al., 2009).

Sharing the diverse stories of experienced research teams working across complex and diverse populations and settings has many benefits. It can





help prevent repeating past mistakes, thereby minimising unnecessary costs and burdens imposed on study participants and their communities (Morgan et al., 2018). The Central Australian Aboriginal Congress (Congress) has partnered with researchers from the University of Melbourne (UoM) and Murdoch Children's Research Institute (MCRI) to examine the feasibility of establishing an early life cohort study of young Aboriginal and Torres Strait Islander children living in Alice Springs, Australia. To inform this initiative, this qualitative study collated strategies used by researchers from their collective experiences of working with Aboriginal and Torres Strait Islander children and young people across Australia. The specific aims were to (1) present a summary of lessons learnt by researchers working to implement longitudinal research with Aboriginal and Torres Strait Islander children, young people and their families; and (2) consider implications of these lessons in planning future longitudinal research efforts in Alice Springs.

Methods

Study design and sampling

To explore researchers' experiences, a qualitative descriptive design with semi-structured interviews was adopted. A systematic review identified 210 longitudinal studies of Indigenous children globally, including 32 Australian prospective cohort studies (Lloyd-Johnsen et al., 2021). Researchers from 10 selected Australian studies of Aboriginal and Torres Strait Islander children or young people were targeted. These studies are known for their strong Aboriginal and Torres Strait Islander leadership, high retention rates, multiple data collection waves, extended follow-up or relevance to Central Australia. A two-stage purposive sampling approach involved emailing invitations to lead investigators, who then nominated interested team members to be interviewed. Snowball sampling identified additional researchers to interview.

Researchers were aged ≥ 18 years and employed on one of the targeted cohort studies for a minimum of 6 months. Written consent was obtained from all researchers after receiving detailed information about the study.

Data collection

A qualitative researcher with prior experience (CLJ) conducted the interviews. The research partners at Congress helped refine and pilot test the interview guide (Appendix 1). With consent, interviews were digitally recorded, transcribed verbatim and cross-checked. Researchers were invited to review and approve interview transcripts and quotes used in an early draft of the manuscript. Interpretation of results was discussed, clarified and resolved to the satisfaction of each individual. No substantive changes were made because of these discussions. Precautions were taken to safeguard the identities of the interviewed researchers and their communities; hence, selected quotes are not linked to specific locations or studies.

Data analysis

This phenomenological study (Sokolowski, 2000) used Braun and Clarke's reflexive thematic analysis (Braun & Clarke 2006, 2013, 2019, 2021, 2022). Immersion in the dataset occurred by reading and rereading each transcript several times. Transcripts were then imported into NVivo (Version 12, 2012, QSR) and systematically coded line by line into preliminary nodes using a bottom-up approach. Initial nodes, capturing explicit and implicit meanings, were refined and expanded through iterative coding. Candidate themes were developed, and visual mapping organised them. A collaborative meeting was held with all authors to finalise theme names conveying shared meanings across the dataset. The final write-up integrated data extracts and analytical narrative in response to the research question.



Ethical considerations

This paper is part of a broader study endorsed by the Congress Research Sub-Committee and granted ethics approval from the Royal Children's Hospital Human Ethics Research Committee (2019.155) and Central Australian Human Research Ethics Committee (CA-19-3519). Aboriginal and Torres Strait Islander leaders are represented on the Congress Research Sub-Committee, which exists to support and promote research that is responsive to the needs of the local Aboriginal and Torres Strait Islander community in Alice Springs. The research was conducted in accordance with the ethical guidelines for conducting research involving Aboriginal and Torres Strait Islander communities (Congress, 2021; Thorpe, 2021; NHMRC, 2003, 2006, 2007, 2018c, 2018a, 2018b, 2023; AIATSIS, 2020; SAHMRI, 2014, 2021) and has been reported using the CONSIDER statement (Appendix 2) and COREQ checklist (Appendix 3).

Results

The 10 targeted studies recruited Aboriginal and Torres Strait Islander study participants from urban, regional and remote sites across Victoria, South Australia, New South Wales, Queensland, Western Australia and the Northern Territory (See Figure 1). These studies include: (1) [Pregnancy and Neonatal Diabetes Outcomes in Remote Australia \(PANDORA\)](#); (2) [Footprints in Time/ The Longitudinal Study of Indigenous Children \(LSIC\)](#); (3) [The Aboriginal Birth Cohort \(ABC\)](#); (4) [Next Generation: Youth Wellbeing Study](#); (5) [Study of Environment on Aboriginal Resilience and Child Health \(SEARCH\)](#); (6) [Gudaga Study](#); (7) [The Aboriginal Families Study](#); (8) [Antecedents for Renal Disease in Aboriginal Children \(ARDAC\) Study](#); (9) [The Gomerioi Gaaynggal Study](#); and (10) [The Indigenous Birthing in an Urban Setting \(IBUS\) Study](#). The targeted studies varied in research scope (Table 1), with recruitment during pregnancy ($n = 3$), at birth or by 6 weeks of age ($n = 3$)

and from 4–6 months postnatal age ($n = 2$). Others focused on children and young people aged 10–24 years ($n = 2$). Cohort sizes ranged 159–1,949 study participants at baseline, collectively recruiting ~9,220 Aboriginal and Torres Strait Islander individuals (Table 1).

Thematic analysis

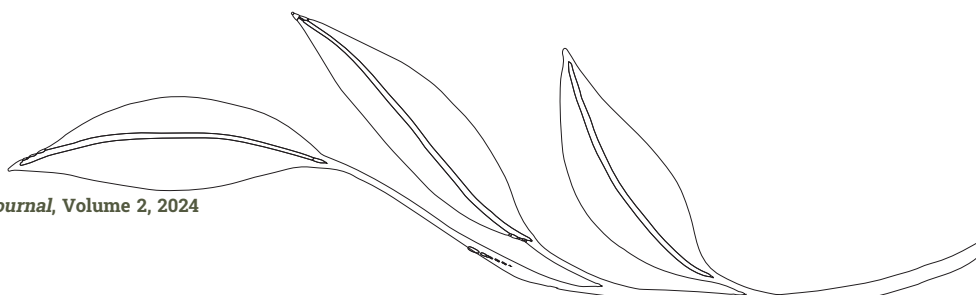
Between February and August 2022, 18 individuals with relevant experience were interviewed. Nearly half (44.5%) identified as Aboriginal and/or Torres Strait Islanders. There was a wide range of work experience with Aboriginal and Torres Strait Islander communities among those interviewed, ranging 7–32 years (Table 2). Interviews, lasting 41–83 minutes, were conducted online ($n = 17$) and in-person ($n = 1$). Transcripts were checked by 72.2% of researchers interviewed, with four providing minor amendments. Four overarching themes were produced from the dataset: (1) Getting things just right; (2) Build and nurture connections with community and staff; (3) 'Sit and yarn with them': Approaches to recruitment and retention; and (4) Great responsibility.

Theme 1: Getting things just right

This first theme examines the practical challenges researchers face in balancing scientific rigour, institutional demands, community priorities and logistical issues in complex environments. Three subthemes included: (a) pragmatic design decisions, (b) survey development and piloting, and (c) funding constraints.

Subtheme (a) Pragmatic design decisions

This subtheme explores the practical decisions that researchers described making in the design and ongoing management of their longitudinal cohort studies. Optimal visit frequency and intervals varied among targeted studies, contingent on the child's age and study goals. For those recruiting at birth or infancy, researchers typically aimed for at least four visits in the first 12



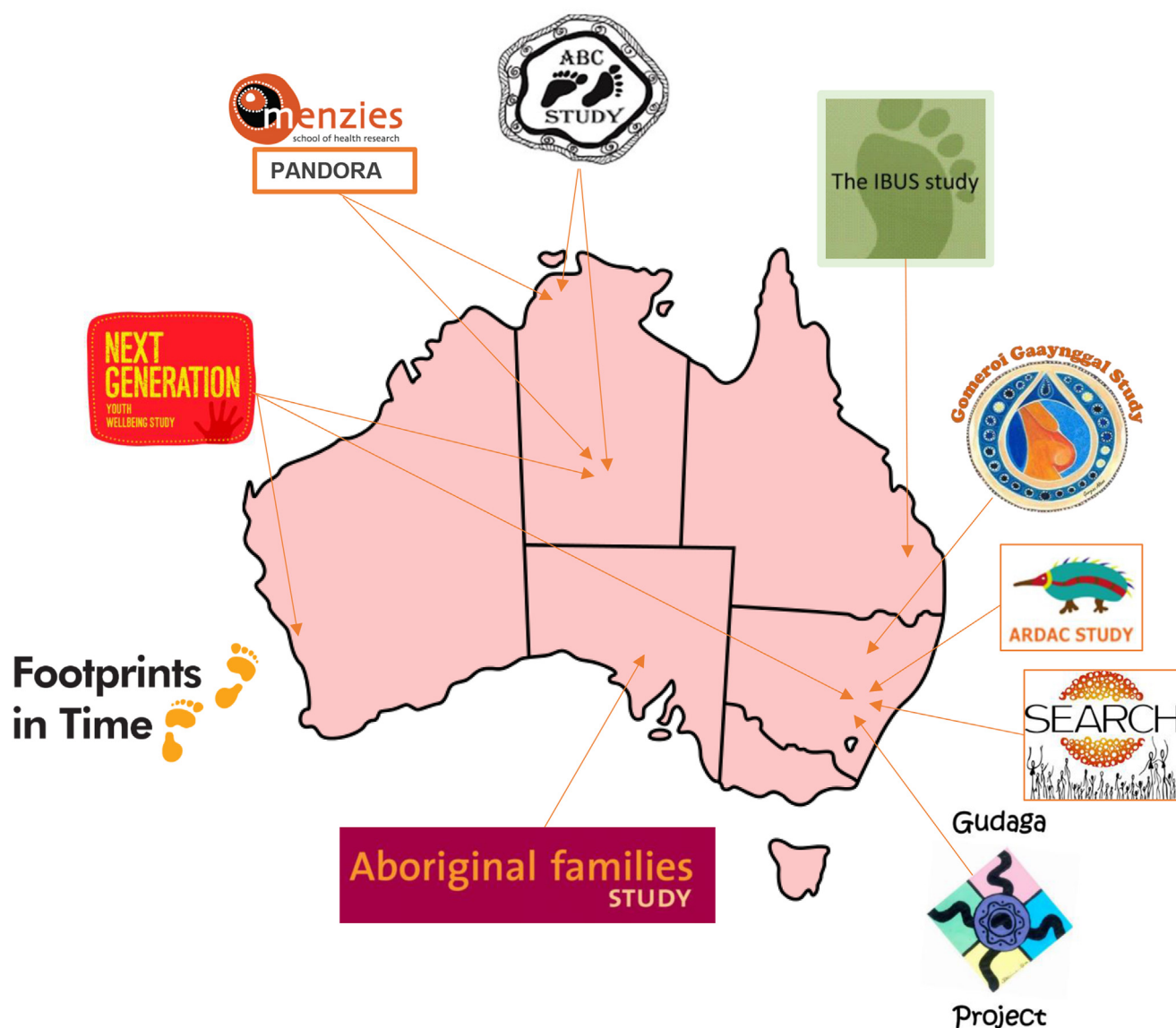


Figure 1: Map of Australia showing approximate study locations.

NOTE: The Longitudinal Study of Indigenous Children (LSIC), also known as “Footprints in Time” included 11 recruitment sites across the Northern Territory, Queensland, New South Wales, Victoria, Western Australia & South Australia.

months of life. As children reached school age, some favoured annual or biannual visits. Maintaining a delicate balance between collecting necessary data and not overwhelming families was emphasised by many, highlighting the challenge of preserving engagement throughout the study.

Several researchers discussed the potential for ‘scope creep’, when the volume and depth of data being collected impacts feasibility:

I’d often... ask the question... ‘Why are we collecting so much data?’...I think being a longitudinal study they just



STUDY NAME (REFERENCE)	STUDY DESIGN	PERIOD	POPULATION (LOCATION)	STUDY AIMS	SAMPLE SIZE (Indigenous %)	DATA COLLECTION	RETENTION RATE	BIOSPECIMENS	DATA LINKAGE
Aboriginal Birth Cohort Study	Prospective Birth Cohort Study	1987 to present	Australian Aboriginal/Torres Strait Islander (Northern Territory, Australia)	To assess the effect of early life factors, birth and childhood, on physical and mental health across the life course.	686 (100%)	Baseline at birth, then follow-up at 10-11, 18, 26, and 28-33 years of age.	71% at Wave 3 (mean age 18.2 years)	Blood & urine.	Participant data linked to births registry, census/national population surveys & hospital data.
Antecedents for Renal Disease in Aboriginal Children (ARDAC) Study	Prospective Cohort Study	2002 to present	Australian Aboriginal/Torres Strait Islander (New South Wales, Australia)	To determine the prevalence of persistent risk factors for chronic kidney and heart disease in Aboriginal and non-Aboriginal children and young people.	1949 of 3418 (57%)	Baseline at 10 years of age, then follow-up at 12, 14 and 16 years of age.	27.5% to 8 years of age.	Urine.	Participant data linked to maternal child health records.
Gudaga Study	Prospective Cohort Study	2005 to 2012	Australian Aboriginal/Torres Strait Islander (Southwest Sydney, New South Wales, Australia)	To describe the health, development and service use of Aboriginal infants and children from birth to eight years of age.	149 (100%)	Baseline at 2-3 weeks of age, then approx. 6-monthly follow-up until 9 years of age.	85.9% to 9 years of age.	Nil.	Participant data linked to births, deaths registries, emergency department, hospital data, immunisation registry, maternal child health records & perinatal data (birth outcomes)
Australian Longitudinal Study of Indigenous Children (LSIC) "Footprints in Time"	Prospective Cohort Study	2008 to present	Australian Aboriginal/Torres Strait Islander (Australia)	LSIC aims to improve the understanding of, and policy response to, the diverse circumstances faced by Aboriginal and Torres Strait Islander children, their families and communities.	1671 (100%)	Cohort B: Baseline at 6-24 months of age, then approx. annual follow-up. Cohort K: Baseline at 3.5-5 years of age, then approx. annual follow-up.	72.2% to Wave 10.	Nil.	Participant data linked to educational datasets.

(Table 1 continues on next page)





STUDY NAME (REFERENCE)	STUDY DESIGN	PERIOD	POPULATION (LOCATION)	STUDY AIMS	SAMPLE SIZE (Indigenous %)	DATA COLLECTION	RETENTION RATE	BIOSPECIMENS	DATA LINKAGE
(Continued from previous page)									
Study of Environment on Aboriginal Resilience & Child Health (SEARCH)	Prospective Cohort Study	2008 to present	Australian Aboriginal/Torres Strait Islander (New South Wales, Australia)	To focus on Aboriginal community health priorities such as, injury; otitis media; vaccine-preventable conditions; mental health problems; developmental delay; obesity; and risk factors for chronic disease.	1600 (100%)	Baseline at 0-17 yrs, then follow-up 2 years later.	Not reported.	Nil.	Participant data linked to emergency department, hospital data, MBS & PBS.
Gomeri Gaaynggal Study	Prospective Birth Cohort Study	2009 to present	Australian Aboriginal/Torres Strait Islander (Tamworth & Walgett, New South Wales, Australia)	To explore intrauterine origins of renal disease, diabetes and growth in order to inform the development of health programmes for Indigenous Australian women and children.	241 (100%)	Baseline in T1, then follow-up in T2, T3, 3, 6, 12 months of age and 2, 3, 4, 5, 6, 7, 8, 9 and 10 years of age.	Not Reported.	Maternal blood, cord blood, child urine & saliva.	Participant data linked to hospital data & perinatal data (birth outcomes).
Aboriginal Families Study (AFS)	Prospective Cohort Study	2007-2008 Consultation 2010 Pilot Study 2011 to date	Australian Aboriginal/Torres Strait Islander (South Australia, Australia)	To investigate the health and well-being of Aboriginal children and their mothers living in urban, regional and remote areas of South Australia.	344 (100%)	Baseline at 4-12 months, then follow-up at 6-7 years of age.	71.5% to Wave 2.	Nil.	Planned.
Pregnancy and Neonatal Diabetes Outcomes in Remote Australia (PANDORA) Study	Prospective Birth Cohort Study	2011 to present	Women giving birth in the Northern Territory, Australia (45.7% Aboriginal & 0.4% Torres Strait Islander)	To assess risks for cardio-metabolic conditions in mothers and their offspring exposed and not exposed to hyperglycaemia in pregnancy (gestational diabetes mellitus, type 1 or type 2 diabetes).	Mothers: 534 of 1139 (46.9%) Children: 550 of 1170 (47%) The study is currently recruiting siblings of Aboriginal and Torres Strait Islander child participants who had a different hyperglycaemia in pregnancy exposure.	Baseline: Pregnancy and birth, post-partum surveys and data linkage: 6 weeks, 6 months, 24 months, 3 years. Wave 1 physical assessment: 18 to 60 months. Wave 2 physical assessment: 5.5 to 13 years of age.	Mothers: 1088 Children: 1109 Numbers eligible for follow-up in Wave 2 study.	Cord blood, buccal swabs (mother at birth, mother and child at Wave 1 and Wave 2), venous blood (mother and child at Wave 1 and Wave 2), urine (mother and child at Wave 1 and Wave 2), blood spot cards & neonatal faeces.	Participant consent includes options to collect health, medical, pathology and education information from registries and government databases using data linkage.

(Table 1 continues on next page)



STUDY NAME (REFERENCE)	STUDY DESIGN	PERIOD	POPULATION (LOCATION)	STUDY AIMS	SAMPLE SIZE (Indigenous %)	DATA COLLECTION	RETENTION RATE	BIOSPECIMENS	DATA LINKAGE
(Continued from previous page)									
The Indigenous Birthing in an Urban Setting (IBUS) Study	Mixed Cohort Study	2015 to 2019	Australian Aboriginal/Torres Strait Islander (Queensland, Australia)	To evaluate the feasibility, acceptability, sustainability, clinical and cost-effectiveness of a 'Birthing on Country' model of care for Aboriginal and Torres Strait Islander families in an urban setting.	770 (100%)	Baseline at 20 weeks gestation, then follow up at 36 weeks gestation, 2 and 6 months postnatal.	Not reported.	Nil.	Participant data linked to births, registry, hospital data & perinatal data (birth outcomes).
Next Generation Youth Well-being Study	Mixed Cohort Study	2018 to date	Australian Aboriginal/Torres Strait Islander (Western Australia, New South Wales & the Northern Territory, Australia)	To explore the views of Aboriginal adolescents, their parents/caregivers and youth healthcare providers on the importance of health and well-being, and to describe the social and environmental context and identify factors relating to resilience, risk behaviours, physical and mental health outcomes over time.	1300 (100%)	Baseline at 10-24 years of age, then follow-up 12 and 24-months post baseline.	Not reported.	Child blood & urine.	Participant data linked to immunisation registry, Medicare Benefits Schedule (MBS) & Pharmaceutical Benefits Scheme (PBS).

Table 1: Study characteristics of the identified individual studies (n = 10)





PARTICIPANT CHARACTERISTICS		
	Number	Percentage (%)
Gender		
Female	18	100
Male	0	0
Identified as Aboriginal and/or Torres Strait Islander		
Yes	8	44.5
No	10	55.5
Role		
Research Officer/Community Research Partner	9	50
Project Coordinator	2	11.2
Principle or Associate Investigator	7	38.8
Years of experience working with Aboriginal communities		
1–9	2	11.1
10–19	7	38.9
20–29	5	27.8
> 30	4	22.2

Table 2: Participant characteristics

wanted to collect everything while they had the opportunity. And I guess my concern was [what's this got to do with the aim of study?] Female Aboriginal and Torres Strait Islander Researcher (S2P17).

Researchers were conscious of the need to avoid collecting excessive or unnecessary data:

I think the biggest debate is... how many things do you measure... every investigator wants all the detailed data collected from a cohort study. They want... everything under the sun... And you just... have to balance that with the burden on the participant and retaining them in a cohort. Female Non-Aboriginal Researcher (S2P3).

Cleaning data between visits posed challenges, especially with a small team, a large participant sample and frequent follow-ups. It was suggested that the recruitment period could be extended for downstream feasibility, but it was noted to impact budgets and timelines:

We knew from our experience... how challenging [follow-up] is in this context... We didn't want to be more optimistic than we thought was feasible... We definitely had some sample size calculations... [but] part of it was practicalities, funding, timing. In the end we just... called a date. Female Non-Aboriginal Researcher (S2P3).

Most researchers agreed that assessments should last no longer than 1–1.5 hours, including time for informed consent. The data should be collected in priority order, so if study participants are time-poor, the core items can still be gathered.

Careful planning for equipment and resources was deemed essential. Many studies used mobile devices for data entry, while some offered hard copy surveys as an alternative. Hard copies served as back-ups when internet coverage was poor or technology failed. Ensuring fieldwork staff had reliable transport and mobile phones was crucial.

Subtheme (b) Survey development and piloting

Each of the targeted studies included administration of various surveys and questionnaires. A common concern, expressed in this subtheme, was the need to minimise burden on families and address community feedback during instrument piloting. This proactive approach engaged community members, ensuring that culturally appropriate questions were adopted. Piloting identified linguistic ambiguities and analysing pilot data was strongly recommended for assessing survey item clarity and relevance.

Subtheme (c) Funding constraints

Researchers recognised the considerable time and effort required to secure and maintain adequate funding for longitudinal research in this subtheme. Staffing and travel costs were the two main budgetary challenges discussed. When funding is uncertain, it is





difficult to offer staff ongoing employment; this risks the loss of staff with community connections and historical knowledge of the study. Researchers stressed the importance of proactive efforts to secure funds to maintain staff employment:

Trying to have attractive job packages for people... Be very proactive about planning [ahead]... if your team members see you actively planning for how that person is going to remain employed... that's really important in nurturing relationships. Female Aboriginal and Torres Strait Islander Researcher (S2P13).

According to one researcher, funding bodies were not always familiar with the true costs:

The [funder] cut our budget... almost by a third... we made a very strong case to [the funder] about the real costs of recruiting families or reconnecting with families in urban, regional and remote locations in a big [state/territory]. Obviously in their wisdom [the funders] didn't think we needed the resources. Female Non-Aboriginal Researcher (S2P15).

Theme 2: Build and nurture connections with community and staff

The second theme contains three subthemes, namely: (a) working collaboratively with communities over time to build trust; (b) giving back to study participants and their communities; and (c) building a solid team of Aboriginal and Torres Strait Islander researchers. All researchers emphasised the importance of building strong and trusted relationships with the community and fellow research staff to ensure sustainability of the research.

Subtheme (a) Working collaboratively with communities over time to build trust

In this subtheme, researchers stressed building early and strong connections with community; identifying key individuals and organisations in each community was

reported as a necessary first step. Working to sustain engagement with these key players was vital. Researchers emphasised the need to proceed slowly, collaboratively addressing local research needs and considering potential impacts. Several studies invested significant lead time working with community to determine the content and design of the proposed research, establish governance structures, build trust and foster positive relationships before funding was sought or research began. This groundwork was deemed essential to success:

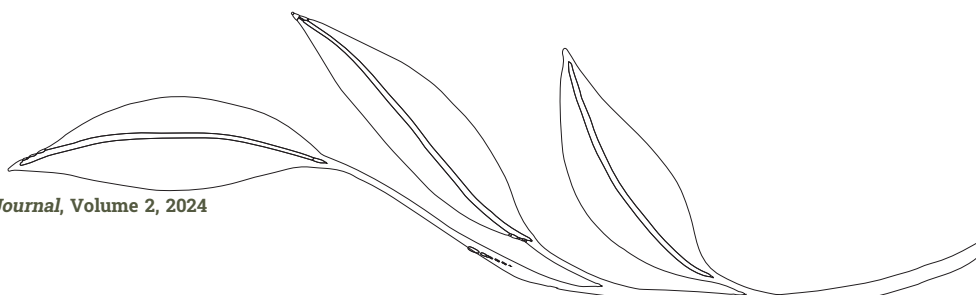
I think just building that relationship, rapport and trust is essential to research and if you don't have it, then it's not gonna be successful at all... My advice is you need to do the groundwork at baseline. Female Aboriginal and Torres Strait Islander Researcher (S2P17).

Subtheme (b) Giving back to study participants and their communities

The need for study participants and their communities to benefit from the research was well understood and expressed in this subtheme. Studies regularly provided feedback of individual clinical results and assessments, providing pathways for additional care or specialist referrals. This was greatly appreciated by families, especially given accessibility issues in some regional, rural and remote communities. A proactive approach to knowledge translation was also emphasised:

You don't wanna be admiring the problem in a cohort study... You want a really clear pipeline [for] how you're gonna use [the] data not seven years down the track but immediately, to go and provide change. Female Non-Aboriginal Researcher (S2P6).

Ongoing engagement initiatives across the studies took many forms. Each was tailored to expressed community needs and delivered in culturally responsive ways. One study organised for regular





visitors to take part in cultural painting sessions while providing important updates on study findings or health education relevant to families:

We had people coming in (physiotherapists, dieticians, occupational therapists, etc) just coming for visits, they would come in and talk to the mums. We made a rule that they don't stand up in front of the mums, they have to sit down... and paint. They [were] learning about our culture and also the mums [were] getting advice. It [was] like a two-way learning process. Female Aboriginal and Torres Strait Islander Researcher (S2P18).

Subtheme (c) Building a solid team of Aboriginal and Torres Strait Islander researchers

In this subtheme, researchers stressed the importance of forming robust research teams with established community connections to ensure longevity and support career progression. They universally agreed that employing Aboriginal and Torres Strait Islander research staff at all levels was essential to success. Recommendations included supporting further education, offering capacity-building opportunities and providing ongoing training. Ensuring a clear career pathway and consistent employment for Aboriginal and Torres Strait Islander staff was highlighted for satisfaction and retention. However, achieving secure employment was acknowledged as challenging due to the insecure nature of research funding. Researchers also stressed the importance of hiring staff with existing community connections:

You've gotta employ people that have existing relationships. There is no time to build that in the life of a project. Female Aboriginal and Torres Strait Islander Researcher (S2P5).

Applicants who were easy-going, friendly and driven were found to be better suited for research roles independent of their previous work experience:

I knew how to talk to people and build up relationships with mob already... I think it might have been more important than any other background because [the investigators] invested a lot of time and resources into giving us all the research skills we needed. Female Aboriginal and Torres Strait Islander Researcher (S2P14).

Hiring Aboriginal research staff in pairs was also described as beneficial. Researchers provided examples of how having a 'buddy' created a more culturally safe and supportive working environment:

I started at the same time as another girl. We liked being able to jump in together and learn about research. It made it less daunting. We were able to bounce off each other... I think if I was by myself, I would've got a bit overwhelmed. Female Aboriginal and Torres Strait Islander Researcher (S2P14).

Researchers recommended enlisting the help of local champions. These powerful allies are highly respected in the community and often have a deep understanding of local issues:

Having local champions who really understand what you're hoping to achieve through the research [is important]. We prefer to call them research partners... they are not just helpers or assistants because partnership is something much more... they are genuinely authentically considered research partners. Female Aboriginal Torres Strait Islander Researcher (S2P13).

Theme 3: 'Sit and yarn with them': Approaches to recruitment and retention

Theme 3 explores the strategies that targeted studies used to effectively engage, recruit and retain cohort participants. This includes four subthemes: (a) recruitment strategies; (b) retention strategies; (c)





known, trusted and safe: the role of brand recognition; and (d) valued contributions.

Subtheme (a) Recruitment strategies

This subtheme discusses effective recruitment strategies for engaging Aboriginal and Torres Strait Islander families. It highlights the importance of building rapport, using culturally appropriate materials and addressing ethical tensions to foster trust and ongoing participation.

Engaging families on hospital wards or in various clinical settings was described as most effective when the objective was to recruit mothers during pregnancy. Additionally, local community centres, health services and schools were reported to be effective recruitment sites. Aboriginal and Torres Strait Islander researchers proved most successful in engaging with children and families. Recruiters worked hard at building rapport with families over time. This simply often meant being regularly seen at recruitment sites and being open to a yarn, not necessarily about research. It helped to demystify their presence in that setting and to build a relationship with potential study participants so that when it did come time to recruit, they were already familiar with them. In comparison, traditional recruitment strategies (e.g. mailed invitations, advertisements, posters or flyers) were less effective.

Visual narratives, such as flip charts or videos recorded in a local Aboriginal and Torres Strait Islander language, were recommended to help convey study information. While initially more costly to produce, the use of culturally appropriate materials helps build trust, demonstrates respect and ensures that the study is accessible and resonates with potential study participants. It was evident from interviews that there is a tension between the requirements of ethics

committees and what is culturally responsive when obtaining written informed consent:

The information statement and consent form... [are] way too long. Who are you writing it for? We're writing it for ethics. I feel very uncomfortable when I take a form that long and give it to somebody who can't read. I feel heavy about that. Female Aboriginal and Torres Strait Islander Researcher (S2P5).

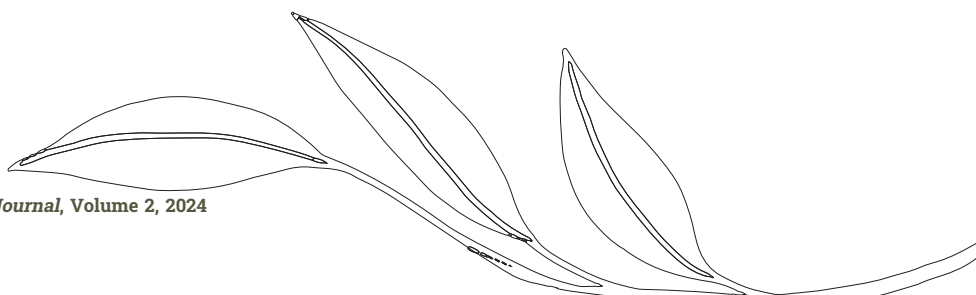
Emphasising that the research is voluntary and that declining to participate will not affect them in any way was also reported as important. Many of the researchers also warned of the need to be mindful of community concerns around privacy and confidentiality, especially in small remote communities where '...everyone knows everyone's business' Female Aboriginal and Torres Strait Islander Researcher (S2P11).

Subtheme (b) Retention strategies

This subtheme explores retention strategies used by researchers to trace Aboriginal and Torres Strait Islander participants and their families, emphasising the importance of maintaining strong community relationships and being flexible in their approach.

High rates of mobility among Aboriginal and Torres Strait Islander families presented one of the greatest challenges to tracing study participants for the researchers interviewed, as described in this subtheme. While transiency made tracing more difficult, it was commonly accepted that the onus was on researchers to maintain strong relationships in community to effectively follow families:

That's hard for us [as researchers but]... we shouldn't be expecting Aboriginal people to be [available all the time]. So, if they want to go out bush... they are entitled to do that. They need to be moving... to get food,



necessities, fuel, to [attend] funerals and ceremony. It's part of their life. Female Aboriginal and Torres Strait Islander Researcher (S2P2).

Balancing the need to remain engaged without becoming intrusive requires careful consideration of contact frequency. Determining factors include study goals, data collection points, staff availability and budget constraints. It is crucial to avoid harassing or 'humbugging' families with busy schedules. Traditional tracing methods involve gathering alternative, but several researchers felt uneasy using these:

I never felt comfortable contacting them through other people because you don't know what happened in this woman's life [since] the last time you've seen them. I didn't wanna come off like: 'Oh, that's the one stalking me for surveys' I didn't wanna be that person. Female Aboriginal and Torres Strait Islander Researcher (S2P14).

Many noted that this method was less effective anyway, given the high rates of mobile phone turnover among Aboriginal communities and mobility within and between communities. Researchers admitted that a face-to-face approach of finding families worked well in rural and remote settings but not as well in urban or metropolitan areas:

We [have] a lot of experience in [longitudinal] follow-up... [For] urban it's about 50%, remote it's about 90%. That is really the big difference. When you go remote, even if the women aren't in community, everyone knows where they are. Whereas in urban [areas] you don't have that same tight knit community and people don't necessarily all know where everyone is. Female Non-Aboriginal Researcher (S2P3).

The use of Facebook was frequently described as a popular means of engaging and retaining study

participants because Facebook accounts rarely change. Using the Messenger function to contact enrolled study participants about upcoming appointments and events seemed to offset some of the logistical issues associated with high mobility.

Approaching trusted local services to act as intermediaries (such as a school or community health service) also helped reconnect families for several of the studies:

We worked with schools to identify families. We got permission from the principal - they would send information about the study to those families without telling us the names. And then those families would tell us if they're interested in taking part. Female Aboriginal and Torres Strait Islander Researcher (S2P16).

Several studies employed a simple and cost-effective method to engage families, which involved taking photographs of the study child at specific timepoints; this approach was highly appreciated. The photos were even used (with permission) in calendars, birthday cards and study newsletters. These small gestures meant a lot to study participants and helped maintain rapport and engagement. Another study used a photograph of the original recruitment team and associated clinical staff to remind parents who they had met at baseline, in case staff turnover or scheduling prevented those individuals attending follow-up visits.

Subtheme (c) Known, trusted and safe: the role of brand recognition

This subtheme included recommendations to establish a recognised 'brand' to help study participants instantly connect with the research team and reduce attrition. Researchers reported designing distinctive logos incorporating Aboriginal and Torres



Strait Islander symbols and storytelling and featuring language in the study name. These practices helped convey special meaning and fostered a sense of pride and belonging. Several studies gave study participants branded clothing, tote bags, hats and drink bottles. Branded shirts worn by staff with Aboriginal and Torres Strait Islander motifs was said to foster culturally safe spaces for participant interaction. Extending branding to study materials, incorporating commissioned Aboriginal and Torres Strait Islander artwork enhanced the overall identity of several studies.

Subtheme (d) Valued contributions

Providing study participants of longitudinal research with appropriate gifts as a gesture of gratitude for their ongoing participation is ethically acceptable, providing the gifts are proportionate to the time involved and are not used as an inducement to participate (NHMRC, 2023). Some of the researchers talked about gift-giving as being an important part of Aboriginal and Torres Strait Islander culture in this subtheme:

You can't take something without giving something back. I think it's only fair... That's part of our culture. It's reciprocal. Female Aboriginal and Torres Strait Islander Researcher (S2P14).

Typical gifts reported included gift cards or gift vouchers. The monetary value ranged AU\$20–100 depending on the number of surveys or interviews completed, the number of hours spent in assessments or the number of family members taking part. Researchers stressed consulting advisory, governance groups, partners, stakeholders and communities before deciding on gift or reimbursement values. A few researchers explained that the value provided had increased over time in line with the rising cost of living, but also due to a push from several advisory or governance groups:

It's not about the stuff that they get. It's about acknowledging people's time and their contribution... to research. We need to acknowledge what they're giving to us. Female Aboriginal and Torres Strait Islander Researcher (S2P17).

Age-appropriate gifts were routinely given to children and young people, including branded singlets or T-shirts, cuddly toys, books, sun hats, drink bottles, paper and colouring pencils or crayons. Some practical things were given out too, including toothbrushes and toothpaste with accompanying oral health messaging in partnership with health services. One study routinely gave out fruit to children on the day of assessments or follow-up visits. Themed fabric bags or totes were also very popular with study participants.

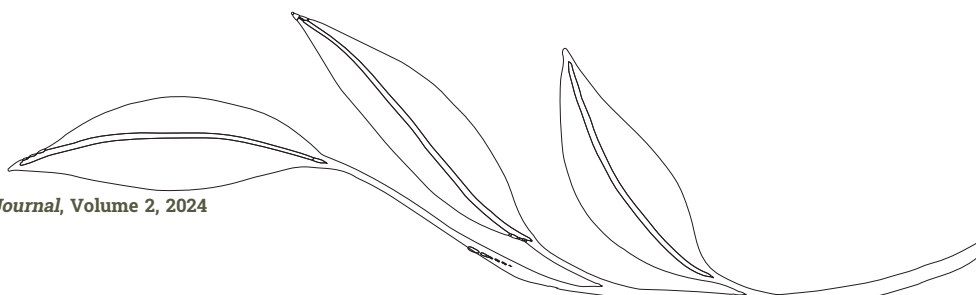
Theme 4: Great responsibility

Five subthemes were included in the fourth and final theme. These were titled: (a) don't put extra burden on families; (b) topics considered 'off limits' or needing careful negotiation; (c) collection of biological samples; (d) culturally responsive research; and (e) Aboriginal and Torres Strait Islander governance and leadership.

Subtheme (a) Don't put extra burden on families

Many researchers acknowledged the large respondent burden placed on busy families who were frequently invited to participate in research in this first subtheme. It is well documented that Indigenous peoples worldwide have been 'over researched'; this was not lost on the researchers:

Don't be a burden on Aboriginal people. I've seen the over servicing of Aboriginal people... at any given time mob that live in communities have up to several visitors each day, several different officers from several different departments looking for them. Female Aboriginal and Torres Strait Islander Researcher (S2P2).





To reduce participant burden, some researchers limited the volume of data and/or assessments collected from families and opted to use existing administrative data. Some partner organisations and study participants were said to have expressed hesitancy, especially with regards to potentially sensitive data belonging to social services and/or justice agencies. Overall, the time and cost constraints associated with third-party data linkage resulted in many studies opting for direct electronic data capture through partnerships with hospitals or health services instead:

We did seek permission for data linkage... but [it's] very expensive and time consuming... Our grant just didn't actually end up covering the cost. We've always had that intention... The cost of doing that has been a barrier. Female Non-Aboriginal Researcher (S2P15).

Subtheme (b) Topics considered 'off limits' or needing careful negotiation

Researchers were asked if they thought there were topics that might be considered 'off limits' or 'taboo'. In response, researchers explained that potentially sensitive topics needed to be carefully negotiated with the support and guidance of an Aboriginal and Torres Strait Islander governance group. Some of the sensitive areas identified are listed in this subtheme, including family or intimate partner violence; involvement with police or the justice system; child maltreatment, child protection; drug and alcohol use; self-harm and suicide; puberty and sexual health. Safety protocols are needed to support staff dealing with the aftereffects of heavy topics. Aboriginal researchers played a vital role in identifying which topics or specific questions would be considered sensitive even before the piloting stage. Some felt strongly about not asking certain questions:

There was [a question]... that they wanted to add, and I was like, 'No, I'm not asking that'... it was about

domestic violence and stuff. As an Aboriginal woman, I can't ask about another woman's man, you know? You just need to be really mindful and sensitive [of] what's culturally appropriate... Unless it's the main focus of the research... then it has to be thought through really well. Female Aboriginal and Torres Strait Islander Researcher (S2P17).

Cultural sensitivities were best addressed when questionnaires, interview guides and surveys were piloted with community input. This study found that researchers needed to be flexible and prepared to pull items or adapt data collection approaches if certain items were found to cause distress or create unsafe situations. When a community prioritises sensitive issues, their guidance is crucial. Communicating clearly about the necessity of sensitive questions is equally vital when interacting with families:

We were discouraged from asking women about the dad... but we were encouraged to ask about cannabis use 'cause the [governance group] were worried about [that]. [Then, in the second wave] the advisory group shifted its view and wanted to know more about [intimate partner violence]. So, we had to nut out how to do that thoughtfully and respectfully... in a way that [made] women feel comfortable. Female Non-Aboriginal Researcher (S2P15).

Subtheme (c) Collection of biological samples

This subtheme covers issues related to the collection of biological samples in half of the targeted cohort studies ($n = 5$, 50%) (Table 1). It highlights some of the procedural challenges noted by researchers, and the critical importance of transparent communication with communities and governance groups regarding the use and storage of these samples.

The potential diagnostic benefit of collecting biological samples outside of routine care was generally agreed





upon. Minimal issues were reported about collection procedures and good uptake was attributed to families' familiarity with regular screening. According to the interviewed researchers, equipment failure impacted sample collection more regularly than refusal to consent. Some felt strongly about avoiding biological samples altogether, unless central to the aim of the study:

It was important to explore with community and partners [which] samples we'd be taking and why... I think the more open conversations you can have earlier, the better. Because people are worried... they just wanna know where the data is going to end up and who's going to look after it... what it's going to be used for. Female Aboriginal and Torres Strait Islander Researcher (S2P13).

Long-term storage and secondary use of stored samples was another issue that was raised. Maintaining a regular dialogue with community and governance groups about the specific use and storage of samples was considered vital. Despite their expressed reservations, most researchers recommended collection of biological samples if central to the study's aims and outcomes. Others recommended accessing results of previous pathology with consent where possible.

Subtheme (d) Culturally responsive research

This subtheme explores the importance of culturally responsive research, emphasising the need for researchers to respect and adhere to Aboriginal and Torres Strait Islander cultural protocols when designing and conducting research. The separation of Men's and Women's Business¹ is another important part of Aboriginal and Torres Strait Islander culture that must be

¹According to Aboriginal and Torres Strait Islander law, certain practices, roles and responsibilities are exclusive to either men or women and are not to be disclosed or observed by the opposite sex. These gender-specific protocols are referred to as 'Men's Business' and 'Women's Business'. Breaches of these protocols can cause distress and shame for Aboriginal and Torres Strait Islander peoples (Fredericks et al., 2021).

considered. Researchers understood the need to be sensitive to these customs when designing and implementing longitudinal research. The need to check in with community at regular intervals was also discussed:

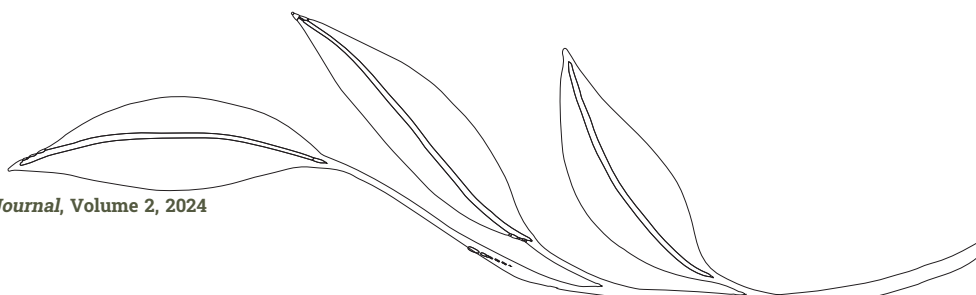
You need to be aware of what's happening in the community if you're going out there. That has to be with phone calls to local [champions] before you go out to a community to make sure that everything's okay for you to visit. Female Aboriginal and Torres Strait Islander Researcher (S2P11).

Adapting fieldwork procedures to accommodate different levels of English was another example of culturally responsive research:

You gotta be careful about the tools that you use. The tablets were too difficult to navigate for participants with low literacy... so we used paper-based surveys [and completed it for them]. A lot of people liked that one-on-one attention 'cause we turned it into yarn. Female Aboriginal and Torres Strait Islander Researcher (S2P5).

One participant spoke of the importance for researchers to be aware of their own positionality and to engage in ongoing self-reflection. Researchers often enjoy a position of privilege, with access to resources and knowledge, which study participants may not have. This imbalance can lead to study participants feeling that they are unable to express themselves freely or have any input and agency over the research process. Being aware of this power differential was important:

[Consider] what you carry around without even being aware of. You've gotta be careful. You've gotta make sure that [as] researchers [we] aren't like seagulls. [They] swoop, take everything, [and] go. I hadn't really thought through [it] before, that research could just be another form of colonisation, invasion and exploitation. But there's that level of responsibility and



accountability in any research project you do. Female Non-Aboriginal Researcher (S2P6).

Subtheme (e) Aboriginal and Torres Strait Islander governance and leadership

The researchers all agreed, in this subtheme, that establishing an Aboriginal and Torres Strait Islander governance or advisory group as early as possible was ideal. Researchers without a formalised Aboriginal and Torres Strait Islander governance group perceived that this fact had negatively impacted recruitment initiatives:

We didn't have... a formal advisory committee, we just had our connections with [partner organisations] individually. It was informal. If we had... established [it] a little bit of earlier... I think the recruitment might have been more successful. Female Non-Aboriginal Researcher S2P1.

Whilst another participant questioned the need for a formalised governance group, arguing that if key relationships were in place and community protocols were followed then it may not be necessary:

If everybody's got... relationships with... all the right people, then you're doing what the governance is going to, you know what I'm saying? In our way, we had our governance in the fact that we operated to protocols. We listened. Governance can also look like this [too]. Female Aboriginal and Torres Strait Islander Researcher S2P5.

A challenge that surfaced for some of the researchers was the coordination of very busy governance group members:

These are [the] people that you'd want... on your committee because they can value add so much, but they're so pushed [for time]. That was the challenge. But when we could get even a few of them together, [it was] so valuable. Female Non-Aboriginal Researcher (S2P8).

Shifting composition was part of the reality of longitudinal research that needed consideration:

Our advisory committee might have seen people come and go but again it's a really important enabler for us because keeping our eye on who's engaged at that level with the study is really important... and making sure we've got the right representation is... absolutely vital. Female Aboriginal and Torres Strait Islander Researcher (S2P13).

It was also considered essential to keep the size of the group manageable but appropriately representative of the region. In addition, it was suggested that members should be paid for their time:

If you're getting a research governance group... it'd have to be paid... compensating people for their time. You need a range of different experts and representation. But you don't want it too big. It's really key to have the purpose of the group set up from the beginning. You want to get that right in the beginning. Female Aboriginal and Torres Strait Islander Researcher S2P2.

Discussion

This study aimed to develop a better understanding of the practical challenges impacting the feasibility of longitudinal research with Aboriginal and Torres Strait Islander children and their families. It analysed the strategies and solutions used by 18 researchers in this field to overcome some of these challenges, and compiled their recommendations and lessons learnt to inform future research. Four key themes were generated from the analysis of the interview data. These themes included reference to common issues encountered in longitudinal research, but also important additional processes required to conduct meaningful, ethical and beneficial research in partnership with Aboriginal and Torres Strait Islander communities.



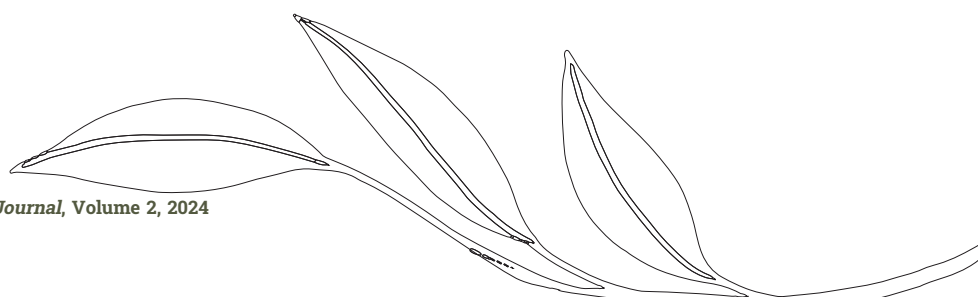
The first theme covered the practical realities of conducting research with diverse communities in complex and dynamic environments. The issue of scope creep emerged. In project management, this refers to the variation or growth of project scope beyond what was originally planned (Kendrick, 2015), impacting timelines and budgets. Longitudinal studies starting in early life often commence with a specific focus, targeting a particular aspect of health and development. However, as evidenced by the systematic review by Townsend et al., these studies frequently evolve and broaden their scope over time to encompass a wide array of variables and factors (Townsend et al., 2016). Collecting a comprehensive array of longitudinal data can yield valuable insights; however, the interviewed researchers were cognisant of the need to avoid collecting excessive or unnecessary data. The increased burden that this places on participants can reduce engagement and lead to attrition, thereby compromising the validity of study findings. The interviewed researchers spoke of the need to clearly justify planned data collections, demonstrating relevance to the research question and community support. While the fundamental concepts of the CARE and FAIR principles of Indigenous data governance (Carroll et al., 2021) are mentioned in some ethical guidelines (AIATSIS, 2020), their explicit integration into ethical practice remains incomplete. There is a pressing need to actively integrate these principles across all levels of research and data management to ensure that Indigenous data sovereignty is not only acknowledged but effectively safeguarded and upheld (Maiam Nayri Wingara, 2018; Walter et al., 2021).

Setting up and maintaining prospective cohort studies is a costly exercise (Costello et al., 2020; Teague et al., 2018; Toledano et al., 2015; Booker et al., 2011).

Assessing required resources is a crucial part of determining study feasibility (Tickle-Degnen, 2013) and

the true costs of conducting longitudinal research are often underestimated (Luo et al., 2010; Eskenazi et al., 2005; Jamieson et al., 2012). According to Jamieson et al., many projects are underfunded. Researchers commented on the increased cost of conducting research with Aboriginal and Torres Strait Islander families living in rural, remote and very remote communities, as has been reported elsewhere (Jamieson et al., 2012; Clough, 2006). The time needed for meaningful community engagement was also mentioned as being frequently misjudged. Strict timelines imposed by academic institutions and funding bodies were said to be contrary to Aboriginal and Torres Strait Islander community processes (Street et al., 2007). Unforeseen circumstances (e.g. Sorry Business²) can delay progress, as well as staff turnover. When planning budgets, Jamieson et al. urge researchers to be realistic about these challenges (Jamieson et al., 2012). Ensuring that longitudinal studies have adequate funding is essential; however, the struggle to secure ongoing funds from finite pools of public research funds adds another layer of complexity for researchers (Doyle et al., 2015). To remain feasible, studies must often reduce scope to deliver study outcomes when fixed budget and limited time frames are imposed (Toledano et al., 2015). Lack of time and funding are major barriers to developing, implementing and disseminating meaningful research with Aboriginal and Torres Strait Islander communities. Funding bodies should acknowledge and accommodate the need for extra resources to cover the true costs of conducting longitudinal research in line with best practice (McGuffog et al., 2023).

²'Sorry Business' is an expression used by Aboriginal and Torres Strait Islander peoples to refer to a period of bereavement and mourning following the death of a community member. It often involves obligations to attend funerals and participate in cultural events or ceremonies.





The second theme framed the importance of fostering strong trusted relationships with community and with fellow research staff to ensure the longevity of the research. Researchers stressed the need for community-centred research with a longer lead time before grants are submitted to ensure that the design and direction of the research align with the needs and values of the community. Being flexible and respecting cultural protocols were also critical lessons. These recommendations are also reflected in the literature (Lin et al., 2020; Bainbridge et al., 2015; Wand, 2008) and across multiple national and state ethical guidelines (NHMRC, 2003, 2006, 2007, 2018c, 2018a, 2018b, 2023; AIATSIS, 2020; SAHMRI, 2014, 2021). As asserted by Bainbridge et al., when researchers and communities work together in partnership, they can accomplish more together than what could be accomplished alone (Bainbridge et al., 2015). By adopting best practices, researchers can foster a collaborative and culturally responsive research environment that promotes meaningful outcomes for all involved.

Investigators of the *Gomerai gaaynggal* study, based in the regional town of Tamworth, New South Wales, spent several years talking to the local Aboriginal and Torres Strait Islander community and partner organisations before any formal research began. Rae et al. recognised that real trust between researchers and community takes time (Rae et al., 2013). Many of the targeted studies formed long-term partnerships over the years with local ACCHS and other Aboriginal and Torres Strait Islander organisations to ensure that the findings were of direct benefit to the community (Wright et al., 2016). The Aboriginal Families Study (AFS), which has followed 344 mother/infant pairs since 2011, grew out of an extended period of consultation with Aboriginal and Torres Strait Islander community organisations across South Australia (Buckskin et al., 2013). The AFS researchers wrote an

exemplar paper charting the social history of the project, including steps taken from initial discussions and establishment of an Aboriginal governance group to the development of the study protocol (Buckskin et al., 2013). Likewise, Dodson and colleagues provided detailed information on the extensive consultation processes used to inform the design and ethos behind the Longitudinal Study of Indigenous Children (LSIC) (Dodson et al., 2012). These are important examples of strong Aboriginal and Torres Strait Islander representation and commitment to community consultation prior to study initiation. In their article, Dodson et al. argue that such consultations are necessary to ensure high response rates and low attrition after the first wave (Dodson et al., 2012).

Ensuring the active participation of Aboriginal and Torres Strait Islanders in all aspects of research undertaken within their communities is not just a best practice but a recognition of their right to self-determination (Kelly et al., 2012). Various ethical guidelines outline how to advance Aboriginal and Torres Strait Islander research governance and participation (Burchill et al., 2023). The current study found unanimous agreement that Aboriginal and Torres Strait Islander governance groups should be set up as early as possible. These governance groups provide valuable insights and perspectives, ensuring that community voices are heard and integrated into the research process. The study also addressed the often-overlooked issue of fair remuneration for advisory board members, an aspect frequently underreported in the literature noted in D'Aprano et al.'s 2023 review of Aboriginal and Torres Strait Islander reference groups (D'Aprano et al., 2023).

The employment of local Aboriginal and Torres Strait Islander researchers was described as vital by all. Hickey et al. encourage others to nurture the



Indigenous workforce by empowering interested community members to become reflexive researchers (Hickey et al., 2018). This was achieved in the Indigenous Birthing in an Urban Setting (IBUS) study by providing ongoing training and mentorship for new Aboriginal researchers. The goal of building Aboriginal and Torres Strait Islander research capacity, according to Kelly et al., is not just to prepare local researchers to conduct research on a specific project, but to ensure that they have the knowledge and skills to conduct research in other fields (Kelly et al., 2012). Jamieson and colleagues recommend that investigators provide ongoing opportunities for Aboriginal and Torres Strait Islander staff to develop their research careers (Jamieson et al., 2012). All the targeted studies employed Aboriginal and Torres Strait Islander staff, and many described their capacity building efforts and support for career progression elsewhere (Sainsbury, 2009; Knight et al., 2009).

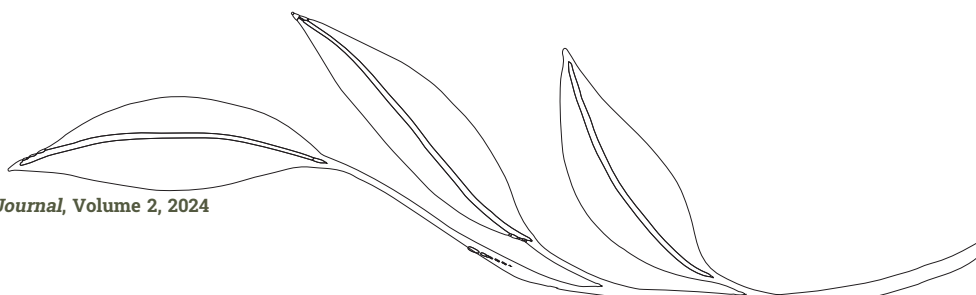
The third theme focused on strategies used to engage, recruit and retain cohort participants. Mobility poses a significant challenge in the longitudinal follow-up of Aboriginal and Torres Strait Islander families. Young Aboriginal and Torres Strait Islander families are said to move more often than non-Aboriginal families (Nikolof et al., 2023). Drivers of periodic or seasonal mobility within and between communities, across towns and cities are a complex mix of social, cultural and economic factors (Martin and Taylor 1995; Smith 2002). This movement has the potential to impact response rates and lead to sample attrition (Dodson et al., 2012). Time taken to travel to geographically dispersed communities to trace study participants also significantly increases the cost of longitudinal follow-up. However, contrary to expectations, researchers described a significant difference in tracing study participants living in urban versus remote communities. In rural, regional and remote

communities, researchers were more easily able to locate lost study participants for follow-up with the help of local social networks in these smaller close-knit communities (Sayers et al., 2009).

Traditional retention techniques such as sending letters, emails or using text message reminders were considered less effective in this population, as previously published (Lawrance et al., 2014). Another method to enhance retention was to establish a study 'brand' that families could recognise and connect with. This was achieved by several of the targeted studies who incorporated Aboriginal and Torres Strait Islander art, language and storytelling into study logos, posters, staff T-shirts and participant gifts. This created a sense of pride and ownership in the study (Sayers et al., 2009).

In the final theme, researchers discussed their many responsibilities to study participants and their communities, emphasising the importance of minimising participant burden and the need for strong Aboriginal and Torres Strait Islander governance and leadership. Leveraging existing administrative data was identified as one way of achieving low impost (Stephens et al., 2021). However, the use of data linkage was underutilised due to cost and time constraints.

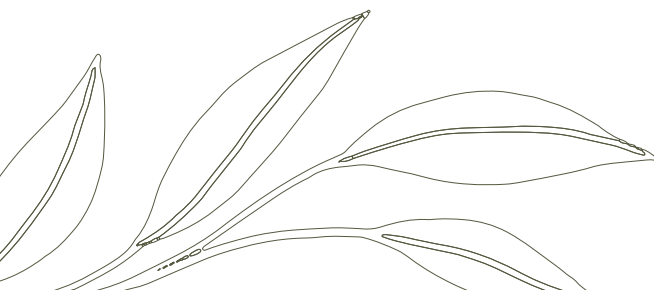
Five of the targeted studies involved the collection of biological samples. Blood and other biological materials hold significant cultural meaning to Aboriginal and Torres Strait Islander peoples, and long-term storage of these samples emerged as another issue that must be delicately negotiated with community (Kowal, 2012; Kowal et al., 2015; Cunningham & Dunbar, 2007; Huria et al., 2019; Walker et al., 2017). Clear explanations of the purpose, benefits and confidentiality of stored samples was considered essential. Maintaining an





TOPIC	APPROACHES USED AND SUGGESTED SOLUTIONS
Aboriginal and Torres Strait Islander governance and leadership	<ul style="list-style-type: none"> ➤ Establish a representative local governance group as early as possible with invested individuals who bring a broad range of knowledge and experience. ➤ Listen actively and be guided by the local governance group and local Aboriginal leaders on all aspects of study design, implementation and translation over the life of the study. ➤ Be flexible and adaptive to changing community needs and priorities over time.
Working collaboratively with communities over time to build trust	<ul style="list-style-type: none"> ➤ Build and nurture connections/trust in community as early as possible. ➤ Take things slow, allow for a long lead-in time. ➤ Work closely to respond to community identified needs.
Building a solid team of Aboriginal researchers and staff	<ul style="list-style-type: none"> ➤ Build a solid team of Aboriginal researchers with existing connections to community. ➤ Ideal applicants are easy-going, friendly individuals who enjoy building rapport/yarning with families, children and young people. ➤ Consider hiring staff in pairs. This provides support, encourages comradeship and helps create a culturally safe work environment. ➤ Have short, medium and long-term plans for career progression and ongoing professional development/training for staff. ➤ Provide attractive salary packages and flexible working arrangements. ➤ Enlist the help of local champions/research partners.
Culturally responsive research	<ul style="list-style-type: none"> ➤ Where possible, use culturally adapted instruments, tools, surveys or assessments. ➤ Be flexible and adapt data collection methods to suit situation (e.g. read interview questions to participants with low literacy levels and turn it into a yarn). ➤ Consider using wordless picture books or culturally appropriate images, animals and incorporate storytelling. ➤ Be aware of local cultural protocols (e.g. women's business, avoidance practices etc.) and plan accordingly. ➤ Be aware of what's happening in community before visiting (e.g. check in with local champions to make sure it's an appropriate time to come – i.e., no sorry business happening). ➤ Be reflective and mindful of own position as a researcher.
Recruitment strategies	<ul style="list-style-type: none"> ➤ Recruiters to be ever present at site (become 'part of the furniture'). ➤ Invest time in conversations over multiple interactions to help build rapport and trust. ➤ Use relationships of support staff in clinical settings to help refer potential participants (word-of-mouth is invaluable and the best kind of promotion). ➤ Avoid sending out written information in the mail or 'cold calling' potential participants. ➤ Create study materials using simple visual narratives such as flip charts or videos in language.
Retention strategies	<ul style="list-style-type: none"> ➤ Carefully consider the frequency of contact/visits to minimise burden on families. ➤ Be flexible with cohort membership – allow families to nominate how much contact they want to have and give them the option to skip visits if they wish without the need to withdraw. ➤ Develop systems to track participant interactions and movements – keep this database up to date. ➤ The use of secondary contacts may not be culturally appropriate – seek advice from governance group and local champions. ➤ Face-to-face approach is the best method to trace families in regional, rural and remote communities (can be less effective in urban settings). ➤ Consider using Facebook Messenger as mobile phone numbers frequently change over time. ➤ Take photographs of children at each visit so they can be gifted back to families or (with consent) incorporated into birthday cards, calendars, newsletters etc. ➤ Take photographs of the original research team to show families at subsequent visits - this may help jog memory and reconnect with families.
Study branding	<ul style="list-style-type: none"> ➤ Establish a study 'brand' incorporating local Aboriginal art, symbols and storytelling (e.g. study logo and colours). ➤ Have staff wear study-branded clothing when interacting with public. ➤ Produce branded study materials (e.g. website, pamphlets, posters etc.) ➤ Produce branded study gifts (e.g. drink bottles, hats, tote bags etc).
Valued contributions	<ul style="list-style-type: none"> ➤ Carefully consider appropriate value for remuneration for participants – seek advice from research partners, governance group and local champions. Be flexible and reactive with changing circumstances over time. ➤ Give age appropriate gifts to children and young people (e.g. study-branded clothing, soft cuddly toys, books, sun hats/caps, drink bottles, paper/colouring pencils or crayons etc.) ➤ Consider use of different themed gift tote bags for different visits. ➤ Consider incorporating age appropriate health education materials in partnership with local health and social services.

(Table 3 continues on next page)





TOPIC	APPROACHES USED AND SUGGESTED SOLUTIONS
(Continued from previous page)	
Sensitive topics needing careful negotiation	<ul style="list-style-type: none"> ➤ Carefully negotiate collection of data on sensitive issues – be guided by expressed community needs and priorities. ➤ Seek input from governance group and local research partners/champions in designing surveys/questions on sensitive issues – make sure to pilot everything with Aboriginal research staff. ➤ Provide clear justification why there is a need to collect sensitive information.
Funding and management of resources/equipment	<ul style="list-style-type: none"> ➤ Be proactive about planning for long-term employment for research staff. ➤ Put forward a strong case to funders about the real cost of recruitment and follow-up of Aboriginal families in regional, rural and remote settings where costs are generally very high. ➤ Make sure fieldwork staff have enough equipment on hand, reliable transport, mobile phones and a contingency plan in place should technology fail.
Data collection	<ul style="list-style-type: none"> ➤ Avoid scope creep – only collect data needed to answer core research questions/aims. Limit ‘nice to have’ questions and seek secondary data sources where possible. ➤ Keep a list of priority data items to collect first if time is short. ➤ Keep visits to 1 hour including time to consent (1.5 hours max, preferably less). This will reduce burden on families and help with long-term follow-up and retention activities. ➤ Be mindful of the fact that many Aboriginal families are over-researched and over-served, use administrative data (where possible) to reduce amount of data collected directly from families. ➤ Annual or biannual visits are acceptable for school aged children (5+ years of age), more frequent visits may be required in early life. ➤ Provide community members with the opportunity to engage piloting to help ensure the language of questions are interpreted as designed and that they are culturally appropriate. ➤ Analyse pilot data before proceeding to determine survey item clarity and relevance. Remove redundant items.
Biological samples	<ul style="list-style-type: none"> ➤ Carefully negotiate collection and storage of biological samples with governance group and research partners. ➤ Only collect biological samples if critical to study aims/outcomes (not simply ‘nice to have’). ➤ Make sure aims behind needing biological samples align with local needs and priorities. ➤ Provide clear plain language justification for collection and storage – linking to local needs and priorities. ➤ Regularly touch base with community to check needs and priorities have not changed.
Data preparation and analysis	<ul style="list-style-type: none"> ➤ Allow sufficient time and resources for data cleaning between visits or stretch out the recruitment period to increase downstream feasibility.
Giving back to participants and their communities	<ul style="list-style-type: none"> ➤ Plan regular culturally responsive engagement activities over course of the study, tailored to expressed community needs. ➤ Incorporate two-way learning. ➤ Have clear protocols in place for returning results and pathways for referral or intervention if required (both for individuals and to broader community).

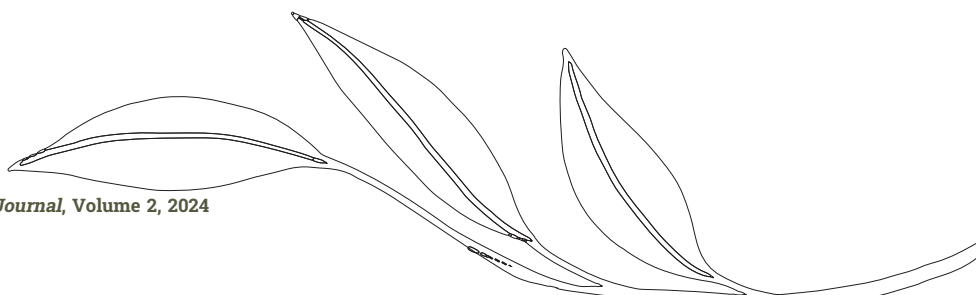
Table 3: Summary of approaches used and suggested solutions

open dialogue on this issue over time was a valuable lesson, as community needs and priorities change.

Reflecting on the collective experiences of the interviewed researchers, this study identified several broad recommendations for longitudinal cohort studies involving Aboriginal and Torres Strait Islander children and their families. The suggested solutions are shown in [Table 3](#). The purpose of these suggestions is to stimulate debate and inform future work in the field.

Strengths and limitations

This qualitative study has several strengths. Nearly half of the interviewed researchers identified as Aboriginal and Torres Strait Islander. The dataset included > 18 hours of audio recordings from interviews with a diverse group of researchers. It was successful in engaging researchers from all 10 of the studies approached, highlighting the willingness of the research community to share knowledge and expertise.





A limitation of this study was the lack of perspectives from male researchers. Despite this, it is believed that the findings reflect the Australian experience, incorporating views from researchers across six states and territories. The authors acknowledge that best practice research with Aboriginal and Torres Strait Islanders is constantly evolving. As such, the synthesis of recommendations and strategies for conducting successful longitudinal research in this context is also likely to develop and change.

Conclusion

While longitudinal studies of Aboriginal and Torres Strait Islander children provide rich insights into the early years, they do face some challenges. These additional considerations are less commonly discussed in the literature. This paper has highlighted certain methodological, practical and ethical issues experienced by researchers representing 10 highly successful longitudinal cohort studies. Lessons learnt included the importance of partnering with community early, building trust over time and attuning the research to meet community needs and priorities. Local Aboriginal and Torres Strait Islander leadership and governance are imperative. Families must not be overburdened, adequate funding must be secured, and Aboriginal and Torres Strait Islander staff must have access to job security and capacity building opportunities. Prioritising two-way learning and feedback loops with community from the outset is extremely important for success. These findings provide a solid basis to progress efforts to co-design a longitudinal cohort study focused on the health and well-being of young Aboriginal and Torres Strait Islander children in Alice Springs (Lloyd-Johnsen et al., 2023), in addition to being useful for other researchers undertaking, or planning to undertake, similar studies within Indigenous populations.

Authors' contributions

Senior Aboriginal author (SE) closely collaborated with non-Aboriginal authors (CLJ, AD and SG) to produce this article. CLJ conceived the initial design of the study. SE facilitated recruitment and CLJ carried out the interviews, conducted the analysis and wrote the first draft of the manuscript. SG, SE and AD advised on research conduct from inception to completion, appraised the analysis process and revised the manuscript. All authors read and approved the final manuscript. The authors alone are responsible for the views expressed in this article and they do not necessarily represent the views, decisions or policies of the institutions with which they are affiliated.

Declaration of interest

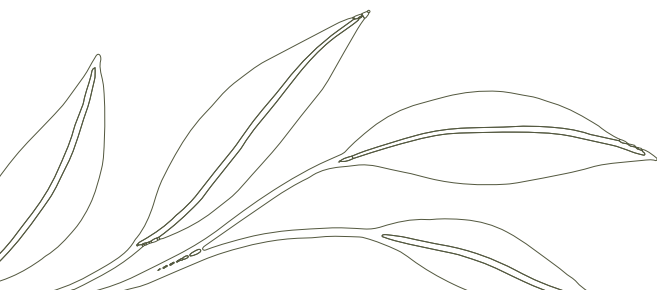
The authors declare that they have no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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spirit of sharing these valuable stories with future researchers striving to work ‘right way’ in partnership with Aboriginal and Torres Strait Islander communities.

Declaration of generative AI in scientific writing

During the preparation of this manuscript the first author (CLJ) used the artificial intelligence (AI) tool [wordtune.com](https://www.wordtune.com) [A121 Labs Ltd] as an aid to improve the readability of some sentences within the manuscript. After using this tool, the first author herself carefully reviewed the AI’s suggested changes and edited the content as needed in her own words. The first author takes full responsibility for the content of the publication.

Availability of data and materials

The dataset used and/or analysed during the current study are available from the corresponding author on reasonable request.

Ethics approval

The findings of this research were reported in accordance with the COREQ checklist for qualitative research ([Appendix 2](#)). Ethical approval for this qualitative study was obtained from both the Royal Children’s Hospital Human Ethics Research Committee and the Central Australian Human Research Ethics Committee in September 2021. This study was conducted in accordance with the ethical guidelines for Aboriginal and Torres Strait Islander Health Research ([NHMRC 2003, 2006, 2007, 2018c, 2018a, 2018b, 2023; AIATSIS 2020; SAHMRI 2014, 2021; Thorpe et al., 2021; Congress 2021](#)).

Author biographies

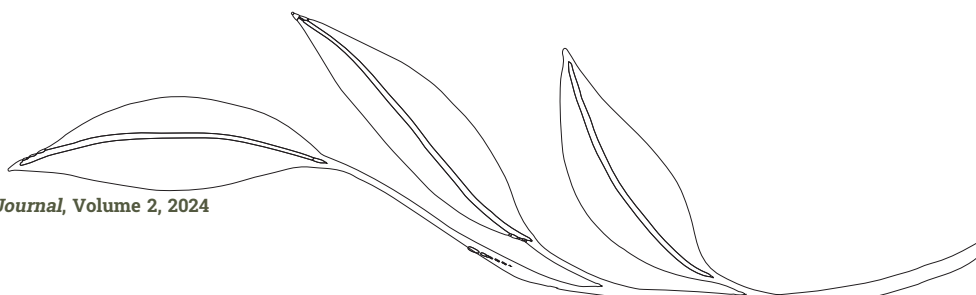
Cat Lloyd-Johnsen

Cat Lloyd-Johnsen is a non-Aboriginal researcher currently undertaking her PhD at the Department of

Paediatrics, University of Melbourne. Cat grew up on Wathawurrung Country along the surf coast of Victoria and is a devoted mother of two school-aged children. She has worked in early childhood research since 2005 at the Murdoch Children’s Research Institute (MCRI) in Melbourne. She previously lived and studied in Norway, where she undertook a brief research project with Adivasi tribal communities in rural India as part of her first Master’s degree. Between 2010 and 2016, Cat supported study investigators to establish and coordinate a large population based longitudinal birth cohort study in the Barwon region of Victoria. Following this, she joined co-authors SE, SG and AD working in the field of Aboriginal health as part of the Policy and Equity research group at MCRI. Cat also works within the Intergenerational Health group at MCRI with Associate Professor Graham Gee and team on cultural healing and recovery from complex trauma. Cat is particularly interested in how early life factors can influence long-term health and wellbeing outcomes for First Nations peoples.

Anita D’Aprano

Associate Professor Anita D’Aprano is a consultant paediatrician and a senior research fellow in Indigenous child health at the Department of Paediatrics, University of Melbourne. Anita undertook her PhD studies in the Northern Territory, exploring developmental monitoring practices in Aboriginal populations, work which led to the creation of the ASQ-TRAK developmental screening tool – the first culturally appropriate tool for use with Australian Aboriginal children. Since completing her PhD, Anita has continued to lead ethical Indigenous child health research, principally in the development of culturally appropriate and validated measures. She has a particular interest and commitment to optimising translational outcomes and in engaging Aboriginal





communities. Her current research program is focused on implementation of the ASQ-TRAK and developing a culturally appropriate early childhood outcome measure for Australian Aboriginal children, the ASQ-STEPS.

Sharon Goldfeld

Professor Sharon Goldfeld is a paediatrician, Director of the Centre for Community Child Health (CCCH) at the Royal Children's Hospital, Co-Group leader of Policy and Equity and Theme Director of the Population Health at the Murdoch Children's Research Institute. She has over decade of experience in state government as a senior policymaker in health and education, including Principal Medical Advisor in the Victorian Department of Education and Training. Her research program is made up of complementary, synergistic and cross-disciplinary streams of work focused on investigating, testing and translating sustainable policy relevant solutions that eliminate inequities for Australia's children.

Sandra Eades

Professor Sandra Eades is a Noongar woman originally from Mount Barker, Western Australia. She moved to Perth with her family at the age of 12. It was during primary school that Sandra decided she wanted to be a doctor but doubted she'd have the opportunity as an Aboriginal girl. In 1985, at the age of 17, she arrived at University of Newcastle as one of four Aboriginal students chosen to study medicine. Eades worked in the public hospital system after graduating from medical school and was a general practitioner with the Aboriginal Medical Service for seven years. In 2003, she graduated from the University of Western Australia with a PhD, the first Aboriginal medical practitioner to do so. She began her academic career researching the epidemiology of Indigenous child health in Australia at

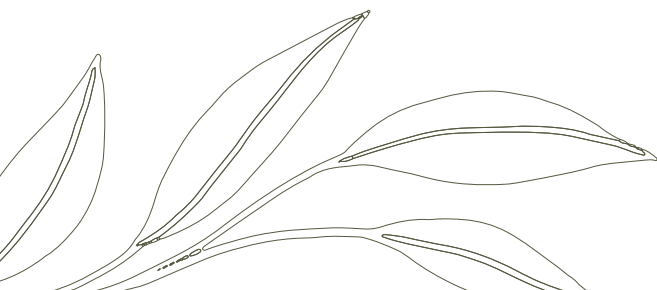
the Telethon Institute for Child Health Research. Sandra's work in paediatric and perinatal epidemiology has improved the lives of Aboriginal women and children. In 2022, she was appointed Officer of the Order of Australia for 'distinguished service to medical research, to Indigenous health, and to professional organisations'. Sandra continues to lead many epidemiological studies across Australia, including projects based in Central Australia. She is currently the Associate Dean (Indigenous) at the Faculty of Medicine, Dentistry and Health Sciences at the University of Melbourne.

Supplementary material

Supplementary material associated with this article can be found in the online version at [10.1016/j.fnhli.2024.100029](https://doi.org/10.1016/j.fnhli.2024.100029)

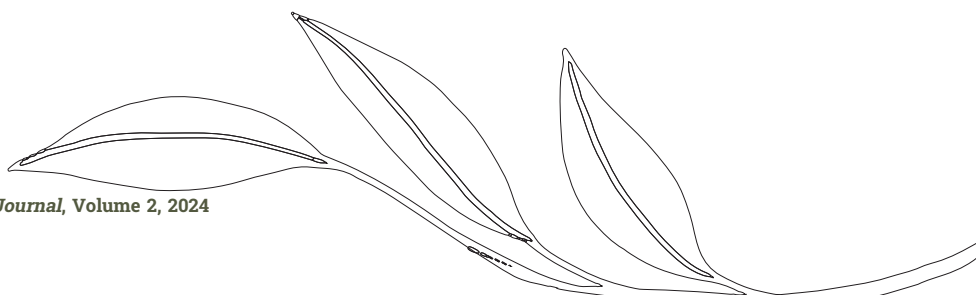
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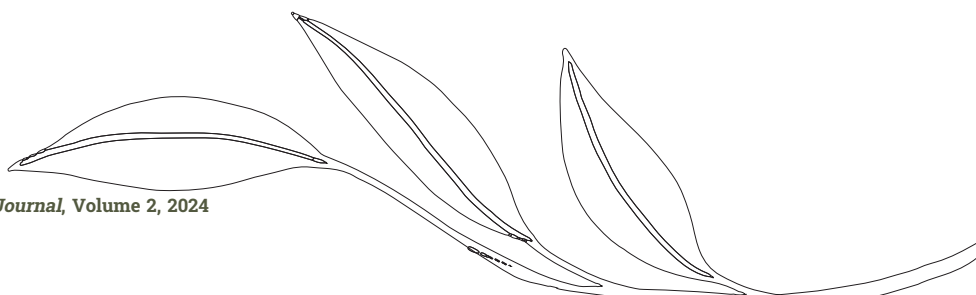
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