The Aboriginal & Torres Strait Islander Research Standards

The KIDS RESEARCH INSTITUTE AUSTRALIA

DISCOVER · PREVENT · CURE

Our artwork

Together 2024

The artwork represents the colours of Australia and the elements symbolise the cultural landscape of the Aboriginal and Torres Strait Islander nations.

Mother earth provides us with food and shelter. The landscapes are covered with vegetation from the saltbush plains to the red dirt and spinifex, to the desert scrub and the mulga and mallee, to the tropical forests.

The river cleanses us and sustains our bodies. It gives us food and a cool place from the hot sun.

The sea is an extended connection to land. It provides us with seafood and enables seafarers to explore other islands.

All nations use the sky to navigate country. It's a guide to season and cultural practices. Certain formations in the sky tells us what foods and animals are around according to the seasons.

Country is important for all the nations. It keeps us strong as it's part of who we are. Our identities are embedded in country, knowing who we are and where we come from makes us strong in body and spirit. Connection to country, spirituality and culture is intrinsic to the social and emotional wellbeing of Aboriginal and Torres Strait Islander people. We are all connected through country and our kinship systems.

The artwork symbolises country and family. It's the coming together of the land, sea and sky. These are embedded in culture and this is what makes families and children strong. The health of our children is paramount to keeping our songlines and stories strong. They are our future so we will ensure the health of our children is at the forefront of everything we do in our research.

This artwork was designed and developed by The Kids Research Institute Australia Aboriginal Art Working Group, comprising Mara West, Valerie Swift, Thomas Betts and Liam Bedford, in consultation with Kevin Wilson at Nani Creative.

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Acknowledgement

The Kids Research Institute Australia acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of the land and waters of Australia. We also acknowledge the Nyoongar Whadjuk, Yawuru, Kariyarra and Kaurna Elders, their people and their lands and waters upon which the Institute is located. We seek their wisdom in our work to improve the health and development of all children.

Foreword

In 2022, the first version of the Standards for the Conduct of Aboriginal and Torres Strait Islander Health Research (The Aboriginal and Torres Strait Islander Research Standards) marked a significant shift in how we, as The Kids Research Institute Australia (The Kids), began to genuinely regard what it means to do research with Aboriginal and Torres Strait Islander peoples.

The initial development was a response to generations of extractive research practices — where Aboriginal and Torres Strait Islander voices were sidelined, and where benefit rarely returned to the communities. Through deep listening, extensive consultation, and the guidance of Elders, researchers, and communities we work with, the Standards brought to life a culturally respectful, community-led framework grounded in Aboriginal and Torres Strait Islander governance, ethics, reciprocity, and relational accountability. It was never a tick box approach — it was a shift in mindset.

This new edition builds on those foundations, reflecting everything we've learned from communities and projects since that first edition was released in 2022. We are excited to see how the second iteration of The Standards strengthens our collective commitment to ethical, high-quality, and impactful research that is led by and meaningful for Aboriginal and Torres Strait Islander communities.

We are particularly proud that this release aligns with The Kids' launch of its new Research Reimagined Strategic Plan and the inaugural Innovate Reconciliation Action Plan — a significant organisational milestone that reflects our broader commitment to reconciliation, systemic change, and genuine partnerships with Aboriginal and Torres Strait Islander peoples

This next step signals not just a continuation, but a deepening of our responsibilities: to walk alongside, to listen carefully, and to ensure that research contributes to real-world, community-defined outcomes. The updated Standards sharpen our focus on Indigenous Data Sovereignty, long-term partnerships, and Aboriginal and Torres Strait Islander leadership across the entire research journey — from conceptualisation to translation.

We are both humbled by the contributions of the many people who have brought their hearts and minds, incredible insight, and knowledge to shaping this new version — and optimistic about the future we're creating together.

Let this not be the end of a development phase, but the beginning of a new chapter where research in Aboriginal and Torres Strait Islander health is defined by Aboriginal and Torres Strait Islander ways of knowing, being and doing.

Glenn Pearson
Director, First Nations Strategy & Leadership

Cheryl Bridge
Head, Kulunga Aboriginal Unit

Introduction

The Kids has developed the Aboriginal and Torres Strait Islander Research Standards second edition aligned to the new strategic plan of Research Reimagined 2025-2035 with the three pillars of Focus, Impact and Thrive.

FOCUS

We will focus our research on solving a defined set of priority problems where we are uniquely placed to add value.

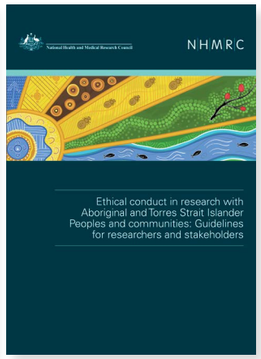
IMPACT

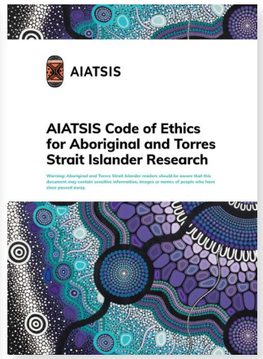
We will deliver tangible solutions with pathways to impact, and grow our research pipeline for tomorrow's breakthroughs.

THRIVE

We will build security for our people and future through an empowered culture, effective governance, diversified funding and streamlined operations.

The guidelines and best practice models that are embedded within the previous strategy of Commitment to Aboriginal Children and families, but importantly are guided by the publications including the National Health and Medical Research Council (NHMRC) Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders 2018 and Keeping research on track II (companion document to the Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities) and Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Code of Ethics for Aboriginal and Torres Strait Islander research.





Introduction to key principles

Indigenous data sovereignty principles

Indigenous data sovereignty is the rights of Indigenous people to exercise ownership over Indigenous data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination and reuse of Indigenous data.

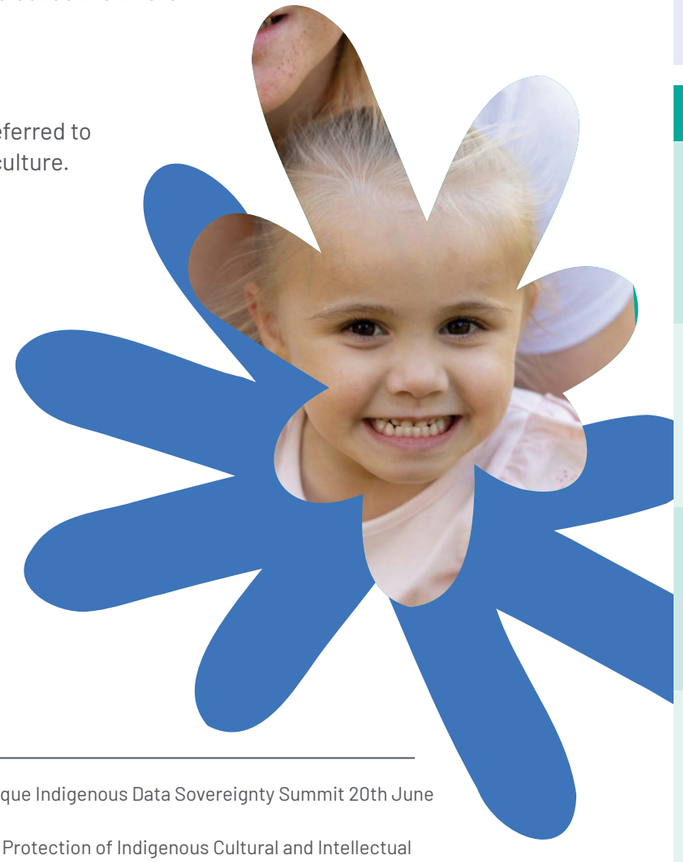
In Australia, Aboriginal and Torres Strait Islander peoples have the right to exert, in relation to their data, that:

- Indigenous peoples should exercise control of the data ecosystem, including creation, development, stewardship, analysis, dissemination and infrastructure;
- Data should be contextual and disaggregated (available and accessible at individual, community and First Nations levels);
- Data should be relevant and empower sustainable self-determination and effective self-governance;
- Data structures should be accountable to Indigenous peoples and First Nations; and
- Data should be protective and respect our individual and collective interests[1].

Indigenous Cultural and Intellectual Property

Indigenous Cultural and Intellectual Property rights often referred to as ICIP, are Aboriginal People's rights to their heritage and culture. ICIP includes:

- Literary, performing and artistic works (see Copyright)
- Languages
- Types of Knowledge, including spiritual knowledge
- Tangible and intangible cultural property
- Indigenous ancestral remains and genetic material
- Cultural environmental resources
- Sites of Indigenous significance
- Documentation of Indigenous heritage[2]



1. Maiam nayri Wingara. (2018). Indigenous Data Sovereignty Communique Indigenous Data Sovereignty Summit 20th June 2018, Canberra, ACT.
2. T Janke, Our Culture: Our Future, Proposals for the Recognition and Protection of Indigenous Cultural and Intellectual Property, (Discussion Paper) Michael Frankel and Company, July 1997
3. Australian Government 2020, National Agreement on Closing the Gap July 2020, viewed 30 May 2025, https://www.closingthegap.gov.au/sites/default/files/2022-09/ctg-national-agreement_apr-21-comm-infra-targets-updated-24-august-2022_0.pdf

Closing the Gap

"Closing the Gap" is a national campaign that aims to address the significant health, education and socio-economic disparities experienced by Aboriginal and Torres Strait Islander people compared to the Australian population. Launched in 2007 the campaign focuses on improving key outcomes such as life expectancy, child mortality access to education, housing, employment and overall wellbeing. The goal is to eliminate these disparities within a generation fostering greater equity, equality and social justice. Closing the Gap is built on collaboration between Aboriginal and Torres Strait Islander communities, governments, organisations and advocated for policies that are responsive to the needs and rights of Aboriginal and Torres Strait Islander people.

The Kids is committed to aligning our research to the Priority Reforms and Targets[3] to make a difference in the lives of Aboriginal and Torres Strait Islander communities.

PRIORITY REFORMS			
Priority Reform 1	**Priority Reform 2**	**Priority Reform 3**	**Priority Reform 4**
Formal Partnerships and Shared Decision Making	Building the Community-Controlled Sector	Transforming Government Organisations	Shared Access to Data and Information at a Regional Level

SOCIO-ECONOMIC OUTCOME AREAS				
1. Everyone enjoys long and healthy lives	**2.** Children are born healthy and strong	**3.** Children are engaged in high quality, culturally appropriate early childhood education in their early years	**4.** Children thrive in their early years	**5.** Students achieve their full learning potential
6. Students reach their full potential through further education pathways	**7.** Youth are engaged in employment or education	**8.** Strong economic participation and development of people and their communities	**9.** People can secure appropriate, affordable housing that is aligned with their priorities and need	
10. Adults are not overrepresented in the criminal justice system	**11.** Young people are not overrepresented in the criminal justice system	**12.** Children are not overrepresented in the child protection system	**13.** Families and households are safe	
14. People enjoy high levels of social and emotional wellbeing	**15.** People maintain a distinctive cultural, spiritual, physical and economic relationship with their land and waters	**16.** Cultures and languages are strong, supported and flourishing	**17.** People have access to information and services enabling participation in informed decision-making regarding their own lives	

The Aboriginal and Torres Strait Islander Research Standards

The Aboriginal and Torres Strait Islander Research Standards are designed to ensure research of importance to the health and wellbeing of Aboriginal and Torres Strait Islander peoples and communities is conducted by and with Aboriginal and Torres Strait Islander people and communities, in a way that ensures the knowledge generated by that research stays with communities.

The Aboriginal and Torres Strait Islander Research Standards represent an evolution of research practice in the Institute that is more in line with Aboriginal and Torres Strait Islander communities' expressed preferences and expectations and sit within the overarching NHMRC's research ethics framework.

Figure 2 | Aboriginal and Torres Strait Islander Research Standards process

What the community has told us

The Institute's values of Collaboration and Respect as articulated in its Research Reimagined Strategic Plan (2025-2035), and are foundations for our research conduct. These values of Collaboration and Respect are consistent with other broader general principles of 'Free, Prior and Informed Consent' (Collaboration); and 'do no harm' (Respect).

The Standards are also imbued with some critical principles. The principles below are taken from the Kimberley Aboriginal Child and Family Health Research Forum (September 2016) which shows the consistencies between Aboriginal and Torres Strait Islander communities and the Institute. The Forum had representation from Aboriginal and Torres Strait Islander communities and health organisations; public sector health and regional development agencies; and The Kids and other health research institutes. A few key governance, executive, research and operations officers from The Kids participated in the Forum.

The principles are included because of the number and range of community voices present at the Forum in 2016. These principles are relevant to how the Institute does its work, and Researchers and other Institute staff should keep these principles in mind when considering Aboriginal and Torres Strait Islander child and family health research. The principles are:

- Research must be community owned
- Communities and researchers must be engaged as equal partners at every step of the way
- Genuine consultation needs to happen directly with the community from the beginning of the research process and should include culture, Elders and young people
- Researchers must regularly check back with communities in the interpretation of results, and communicate research progress and outcomes
- All stakeholders must adhere to local protocols in initiating, conducting, evaluating and translating projects into practice
- Research projects should also build the capacity of Aboriginal and Torres Strait Islander people to do research through transferring research skills, mentoring and delivering tailored training
- Research results must be translated into improved practice, policy and health systems that benefit Aboriginal and Torres Strait Islander people

The Aboriginal and Torres Strait Islander Research Standards process

Research Idea

When thinking about your research idea key questions to consider:

1. Does the community understand and want your research project?
2. How will you embed Aboriginal and Torres Strait Islander Governance and voice in your project?
3. Is your research a community priority?
4. How else will the community be involved in your research project?
5. What direct benefit will the community receive?

What's next? Study close out:

- KAU is here to discuss the completion of your project. Prior to starting your new program of work, we suggest further conversations and brainstorming the conceptual stages of your new research project.
- Sharing your findings not just to your project but wider reach where it could have greater impact.
- Reflect on your learnings from the project journey.

Reporting:

- KAU will continue to work alongside your team to provide support and guidance on reporting back to community and stakeholders.
- Research teams are required to develop a plan to keep community informed throughout the research process.
- Analysis of results together and to be shared with community and stakeholders.

Submission of ethics proposal:

- KAU will issue a Letter of Support, as a statement of support that appropriate due diligence has been followed by the research team in developing their application.
- Some of the relevant Aboriginal and Torres Strait Islander community perspectives and considerations for a successful WAAHEC ethics approval will have already been met if Projects follow the advice for Standards 1, 2 and 3.
- Get in touch with The Kids Research Governance teams

Aboriginal Research Projects Forum (ARPF):

- Further to consulting with science/research/clinical peers, the ARPF is an opportunity to seek further perspectives and insight on your research from a panel of Aboriginal and Torres Strait Islander community members and health researchers.
- The ARPF panel is critical in gaining external Aboriginal and Torres Strait Islander community and cultural perspectives. It also considers your research / science enquiry.

1. **Aboriginal and Torres Strait Islander Governance and Relationships**
2. **Formulate the Research Question**
3. **Proposal and Funding**
4. **Research Governance and Research Ethics Approval**
5. **Project Commencement and Data Collection**
6. **Analysis and Reporting**
7. **Translation**
8. **Evaluation**

IDEATION — PLANNING THE RESEARCH — HOW WE DO OUR RESEARCH — WHAT DID WE FIND OUT — HOW DID WE DO

Contact Kulunga (KAU): Conceptual stage

- KAU can help research projects to engage and build relationships with communities (where Project/Program doesn't have existing relationships or internal capability).
- Engagement needs to be Relational (genuinely considers communities and is NOT Transactional).
- In the first consultation meeting with Kulunga a range of topics will be discussed from inception, governance, and ethics through to completion.

Grants, contracts or philanthropic funding:

- Meet with KAU, Community Engagement and Communications as part of platform review (or seek feedback and guidance for other funding streams as appropriate).
- Platform review will provide necessary advice on critical aspects of successful research design and execution, that are too often missed or given insufficient deliberation (e.g. community consultation, reference groups, communication materials, events, employment, capacity building including workforce and/or training, funding, and honorariums).

Project commencement and data collection (in the field):

- Liaise with KAU team as required to ensure your team understands and follows regional-specific cultural protocols and business practices (e.g. consent forms, employment of Aboriginal and Torres Strait Islander people, community reference groups & meetings with individuals and community organisations).
- Explore opportunities to participate in cultural activities and events to strengthen bonds with community and improve project success.

Translation:

- Ensure proper acknowledgement is promoted (eg all community members who contributed to the research and those who played a major role should be identified as co-authors). It's important to share your findings so research can be applied and truly make a difference.

Note: If at any time there is an amendment to your project, please notify KAU -

Kulunga@thekids.org.au

Standard 1

Aboriginal and Torres Strait Islander Governance and Relationships

1.1 Getting a community perspective and building relationships

Researchers and their teams must engage early with Aboriginal and Torres Strait Islander peoples, communities and organisations, to co-design, and understand and identify their health and wellbeing priorities before developing the research questions and research design. Be clear about why you are wanting to do this project and how community will have a voice. Ensure the research will have meaningful benefit to, and impact on, Aboriginal and Torres Strait Islander communities.

At conceptualisation:

- Meet with the Kulunga team who can guide your team to discuss ideas and connect with communities and external stakeholders
- Use the existing community relationships within your project team and the wider Institute to test the applicability and veracity of the research idea
- Collaborate with other Institute research teams who may already be working in this space and location to reduce burden on the community
- Consider conducting formative research first to understand qualitatively what an issue means to Aboriginal and Torres Strait Islander peoples, if it has not already been done. Consideration of the impact of past research practices that may have been harmful, deficit narratives and assumptions should be viewed with a critical eye
- Conduct a literature review and evaluate previous related research and review grey literature, community reports and oral histories to understand what has worked, what has not and why
- Learn some local context to communities where you are thinking about doing a project (eg. local groups, some local history) and the community's previous experience of research
- Understand that there is rarely ever one perspective in community and therefore, you will need to listen and consider several perspectives on an issue
- Ongoing engagement with community across the research cycle is required
- Connect with the Government Relations team to share project idea and discuss whether any partnership opportunities that can exist with Aboriginal and Torres Strait Islander community-controlled organisations and government stakeholders to drive impact of the intended research

1.2 Ensuring excellence through cultural security

Researchers and their teams have the expertise, self-awareness and cultural understanding to conduct respectful research with Aboriginal and Torres Strait Islander peoples and communities

- Project teams need to build and sustain long lasting relationships that are not transactional
- You will need to identify, understand and navigate cultural protocols, norms and dynamics in the Aboriginal and Torres Strait Islander communities
- Ensure research teams adhere to Men's and Women's Business
- Work with local community to ensure that the research project is culturally safe for community researchers, participants, Elders and others. Grow your understanding of Indigenous research methodologies. Review Lowitja Institute, NHMRC, AIATSIS guidelines and any other relevant resources
- Understand the diversity of Aboriginal and Torres Strait Islander peoples, culture, and context, and acknowledge the ongoing impact of colonisation, government policies and racism

1.3 Aboriginal and Torres Strait Islander leadership and governance

Aboriginal and Torres Strait Islander Governance and leadership is paramount to the success of your project. Effective accountability to Aboriginal and Torres Strait Islander peoples and communities is required

- When setting up your project wherever possible ensure that Aboriginal and Torres Strait Islander Researchers, Chief Investigators lead or Co-lead the research
- Considerations regarding employment of Aboriginal and Torres Strait Islander peoples on your project (eg. researchers, community researchers, other project staff) - employing one Aboriginal and Torres Strait Islander team member is not adequate. This needs to be reflected in budgetary requirements
- Establish an Aboriginal and Torres Strait Islander Governance Committee to operate for the life course of the project. It is very important to establish upfront the purpose and role of the group, including clear terms of reference and remuneration is required
- Acknowledge Aboriginal and Torres Strait Islander peoples within the project including as authors, contributors, co-presenters (where possible. Non-Aboriginal and Torres Strait Islander researchers should not present about the findings of Aboriginal and Torres Strait Islander research without an Aboriginal and Torres Strait Islander co-presenter – ideally these findings are presented by the Aboriginal and Torres Strait Islander people involved)

1.4 Aboriginal and Torres Strait Islander Co-design (start now and continue throughout the project)

As outlined in the Maiam nayri Wingara Indigenous Data Sovereignty Principles, Aboriginal and Torres Strait Islander peoples have the right to ownership and control of their data and the data narrative (Maiam nayri Wingara. (2018)).

- Discuss and co-design project data stewardship and management with the communities. Work with your communities and your Aboriginal and Torres Strait Islander investigators/staff to determine how Aboriginal and Torres Strait Islander peoples will maintain control of the data ecosystem. When required, technical expertise needs to be engaged
- Ensure study design adopts a strengths-based narrative. Discuss how will you ensure the findings are contextualised and protected during and after dissemination
- Discuss and co-design Indigenous Cultural Intellectual Property and other Intellectual Property arrangements with the community
- Ensure agreements and/or clear documentation set out the arrangements between the Institute and Aboriginal and Torres Strait Islander organisations and communities, as well as any other collaborators. You may need a research agreement, contract or Memorandum of Understanding (MOU) with an Aboriginal and Torres Strait Islander community organisation(s) for this project
- If your research involves collection of biological samples discuss with the communities whether they would like the samples repatriated, safely stored and/or destroyed at the end of the project. It may also help to reference the new NHMRC guidelines for ethical donation of tissue and cells. Kulunga, Research Governance and the Institute Biosafety Committee can assist. Certain States have legislation on benefit sharing and commercialisation requirements in biodiscovery legislation (such as Queensland), which may need to be considered depending on location

Community perspectives and relationships are an ongoing activity, that should not only be tied to a specific potential research project. Building and maintaining genuine relationships is a normal part of child health research best practice.

Standard 2 Formulate the Research Question

2.1 Prioritise Aboriginal and Torres Strait Islander peoples' and communities' perspectives

The research idea and questions are established based on the health and wellbeing priority issues identified by Aboriginal and Torres Strait Islander peoples and communities.

- The research idea is formulated and driven by local community directives rather than desk-top research
- Researchers consult with Aboriginal and Torres Strait Islander community members to establish and co-design the research questions
- Researchers should utilise the outcomes of past community consultations, and hold focus groups or workshops that identify community health and wellbeing priorities
- Researchers must be aware that each community-driven consultation is locally and regionally specific. What you identify for one community may not be suitable for others
- National, State and regional priorities may not automatically align with local community priorities. How have you identified, or been informed, about local community priorities? How will you ensure a bottom-up approach?
- Social determinants of health, housing and infrastructure can play a more primary role in Aboriginal and Torres Strait Islander peoples' lives. Does your research topic acknowledge and address these and their potential impacts on health and wellbeing?

2.2 Planning for success: start with the end in mind

Researchers partner with Aboriginal and Torres Strait Islander peoples and communities to plan and co-design how the findings of the research will inform better health and wellbeing outcomes for Aboriginal and Torres Strait Islander peoples and communities beyond the life of the project.

- Clearly state what successful research partnerships look like for all stakeholders. Community defines what success looks like within a research partnership. Clearly identify the specific outcomes and deliverables
- Ask yourself what the project's end goal is. How will the evidence from your study be translated into outcomes for the Aboriginal and Torres Strait Islander community (eg. school programs, health promotion, co-designed changes to policy and practice). Will you work with the Aboriginal and Torres Strait Islander community to advocate that the evidence be translated into changes to service delivery for broader impact?
- Budgets need to include capacity for increasing understanding of Aboriginal and Torres Strait Islander families about health issues through culturally appropriate and accessible information and activities, sharing research results by regular reporting back to Aboriginal and Torres Strait Islander community partners
- Ensure you have sufficient resources to complete your study. If the community offer resources, ensure you have sufficient budget to remunerate them.
- Be open and transparent with stakeholders about who will benefit from the research now and who will benefit from the research into the future. Be honest with community about what the direct benefits to them will be and when those benefits will be delivered.

2.3 Confirm community buy-in and strengthen relationships

Researcher/research team continues to strengthen partnerships with Aboriginal and Torres Strait Islander peoples, communities and organisations, during the planning and design of the research project to ensure tangible strengths-based benefits to Aboriginal and Torres Strait Islander communities.

- Be clear about the stage of the research and the process for it to go ahead. Seek approvals from local Aboriginal Community Controlled Health Organisations (ACCHOs, Aboriginal Medical Services), community councils, government organisations (WACHS, Education etc) and any other organisations identified by the community and work together with these organisations to identify funding opportunities
- Check research project will result in direct net benefit for the Aboriginal and Torres Strait Islander peoples and researchers involved in the research. For example, the benefit outweighs the risks/ inconvenience of being involved
- Benefit should be negotiated with, and understood, as defined by Aboriginal and Torres Strait Islander peoples and/or the community

2.4 Choose the most appropriate methodology(ies) for research proposal

Researchers need to consider methodology, balancing scientific rigour, cultural and ethical imperatives. Methods should be informed by community consultation, negotiation, co-design, and informed consent.

- Negotiate and determine methods together with Aboriginal and Torres Strait Islander participants, communities and the project's Aboriginal and Torres Strait Islander governance
- Consult with Aboriginal and Torres Strait Islander communities early how they would like Indigenous systems and methodologies built into the research design
- Study methods should be co-designed with Aboriginal and Torres Strait Islander communities and be Aboriginal and Torres Strait Islander led
- Acknowledge power imbalances between the researchers and the participants and implement strategies recommended in the NHMRC's National Statement
- Use methods that respect cultural ways of working and ensure Aboriginal and Torres Strait Islander perspectives are heard and acted upon. For example, consider incorporating more qualitative and participatory methods as well as reciprocity
- Methods and timeframes need to be flexible enough to allow for proper two-way knowledge sharing, consultation and negotiation, and to allow for timeline changes for local events and cultural business
- Ensure there are adequate resources for genuine engagement (eg. time, staff including on the ground community staff)

Standard 3 Proposal and Funding

3.1 Develop research and funding proposal

The proposal is of high quality and achieves best practice in Aboriginal and Torres Strait Islander Health & Wellbeing Research.

- Make sure your proposal considers and includes the actions from the previous steps particularly that it takes into consideration the broad perspectives and priorities of the community, has strong Aboriginal and Torres Strait Islander governance and is culturally relevant, appropriate and safe
- Having Aboriginal and Torres Strait Islander Investigators and cultural knowledge holders from the community involved in the development of your proposal will have far reaching benefits
- The proposal includes clear articulation of your engagement with and involvement/co-design of the community before, during and after the research project. Ensure you budget sufficiently to allow for proper, timely and respectful engagement/co-design.
- The research proposal meets the NHMRC guidelines and Indigenous Research Excellence Criteria.

3.2 Update community and/or external stakeholders about funding opportunities

Stay connected with community and external stakeholders to keep them informed of your funding application progress and outcomes

- If the community has a funding schedule for engaging in research with them, ensure that you have available funding to meet these research costs (including any upfront fees for pre-research discussions and engagement)
- Be clear about funding timelines and update people when details change
- Agreed benefits should include capacity building and employment, and value being placed on the in-kind and unfunded support that Aboriginal and Torres Strait Islander organisations and community members are willing to provide to you/the project (eg. for time attending meetings, discussing/co-designing the project, using premises, vehicles etc). Ensure research budgets cover costs such as backfilling positions, using partners' facilities, transport, administration, and interpreters

3.3 Consider Intellectual Property ownership and affirm Indigenous Cultural and Intellectual (ICIP) Property rights

Researchers recognise and respect the Indigenous Cultural and Intellectual Property (ICIP) rights and Indigenous Data Sovereignty rights of Aboriginal and Torres Strait Islander communities and individuals to cultural knowledge systems, data and biological samples generated or collected during research

- Intellectual Property ownership, including ICIP and future use of samples are discussed and agreed with all participating Aboriginal and Torres Strait Islander organisations, community members and/or Aboriginal and Torres Strait Islander community representatives. These arrangements need to be documented in contracts and/or Memorandums of Understanding, so ensure you consult with the Legal and Contracts teams to develop these documents. Any data collection must not occur before ethics and the relevant organisational Aboriginal and Torres Strait Islander governance and research governance approval(s) have been obtained.
- Consider if there is potential for patents and/or commercialisation from the project's findings. If any potential is identified, discussions and agreements about benefit sharing need to be had with Aboriginal and Torres Strait Islander stakeholders on the project. The Innovation and Commercialisation Team can advise and support you through this process.
- Participant information sheets and consent forms (PICFs) should make it clear who owns the data and how data and samples will be securely stored, who can access them and how they could be used in the future. It is highly recommended, to seek advice for consent for future use of data and samples prior to gaining approvals from Aboriginal and Torres Strait Islander Human Research Ethics Committee and relevant organisations. Ensure you make clear within your PICFs the procedure for withdrawal should a participant wish to, and at what happens to any data already collected.
- Ensure Aboriginal and Torres Strait Islander communities and researchers are familiar with the principles of Indigenous Data Sovereignty and find practical, useful ways to return data and other research outcomes to communities and organisations.
- Indigenous data sovereignty continues beyond the life course of the project. Determine how long the project's data needs to be kept for post-project and have discussions with Aboriginal and Torres Strait Islander communities and the project's Aboriginal and Torres Strait Islander governance about how the data will be managed and protected during this time.
- Data Governance can advise about data retention times and procedures, and the Information and Communications Technology (ICT) team can advise on procedures for data storage and security

Standard 4 Research Governance and Research Ethics Approval

4.1 Engage with relevant jurisdictional Aboriginal and Torres Strait Islander health & planning forums (eg. Kimberley Aboriginal Health Planning Forum & Pilbara Aboriginal Health Forum)

- Researchers who actively engage with Aboriginal and Torres Strait Islander Planning forums benefit from local input and establish ongoing relationships for the interpretation and implementation of results and for future research proposals
- Local health and planning forums are a great source of regional knowledge and strategic priorities
- Consult early with local regional Aboriginal and Torres Strait Islander health & planning forums. In some regions you will not receive ethics approval for your study without endorsement from the local forum(s)

4.2 Develop research protocol

Consider the following:

- Confirm with the community that the research is still a priority based on your earlier consultations, meetings and discussions
- Training and employment of local people and community members (e.g. good clinical practice, data collection, consent process, cultural navigation, cultural governance and protocols)
- Engage the community through the arts where possible (artists, storytellers, interpreters, writers, actors, etc). Seek permission from the artist before using any art in your project and ensure you acknowledge the artist for any works used. If you wish to purchase artwork for your project consult the Institute's Purchasing Aboriginal and Torres Strait Islander Art Guideline and speak with the Kulunga team
- Remember - the people most equipped to ensure research is undertaken and implemented in a culturally secure way are people from the same community
- Ensure you adopt a strengths-based design in your protocol and embed opportunities for Aboriginal and Torres Strait Islander people, communities and organisations to co-design the interpretation of the results, or at the very least comment on results and reports, before they are released
- Information dissemination – consider how you will achieve information reciprocity throughout and after your study. Information you share can include the health information provided throughout the course of the study, as well as the study findings and how they contribute to improve health outcomes of Aboriginal and Torres Strait Islander people and communities

4.3 Develop ethics and governance applications (confirm community governance and participation)

Ensure the information and consent forms, and informed consent process are appropriate for the Aboriginal and Torres Strait Islander people's culture, language and understanding. Be aware that Aboriginal and Torres Strait Islander people and communities are diverse and the forms and processes that are appropriate for one community may not be appropriate for another.

- You should engage with a local navigator to ensure the language, artwork and consent processes are appropriate for that community. You need to consider that English may not be the first language of the community. In which case, a translator must be engaged. It is also important to consult your navigator about whether your study relates to any cultural business (eg. Men's and/or Women's business) and ensure your study respects these processes. For example, when visiting any community, ensure your team is of mixed gender to allow for appropriate contact with all relevant persons in the community. Consent processes can be in writing or verbal with written confirmation (if you have approval from an ethics committee) so ensure your processes are flexible and able to accommodate different consent processes.
- For online or digital surveys an explanation and option acknowledging consent without a signature (to ensure privacy and anonymity) maybe appropriate – consulting with the community will identify consent methods that are most suitable for them
- Gain letters of support from relevant Aboriginal and Torres Strait Islander communities in the region where research will be undertaken
- Submit and gain support from the Aboriginal and Torres Strait Islander Planning Forums in relevant state jurisdictions.
- Ethics and research governance at the relevant organisations involved must be approved before starting the research. Consult with the Research Governance team (researchgovernance@thekids.org.au) if you have queries about consent processes
- Consult with Kulunga at conceptualisation stage. Kulunga will outline the ethics process and in particular gaining a letter of support to submit an application to Western Australian Aboriginal Health Ethics Council (WAAHEC)
- Develop relevant agreements for the protection of participants, their data and samples, as well as data and IP ownership
- Confirm your Aboriginal and Torres Strait Islander Governance for the project such as Community Reference Groups or Advisory Groups

Standard 5 Project Commencement and Data Collection

5.1 Hold "kick-off" meeting

Schedule a kick-off meeting and periodic status updates with community and stakeholders. Encourage active participation and input

- Researchers must keep people and communities informed of the progress of the research even when not in community. Ask how community wish to receive feedback - through an email update, flyers, events etc
- Maintain community relationships and participate in important community event
- Think about the NHMRC's six core values for Aboriginal and Torres Strait Islander research (eg. Reciprocity) and how you give back to the communities you work within
- Be clear about your timelines and update all key stakeholders, including community, when things change

5.2 Employ local, build capability and understand cultural protocols

- Research is conducted with Aboriginal and Torres Strait Islander people and in Aboriginal and Torres Strait Islander communities in accordance with local cultural protocols, including protocols around reciprocity and knowledge exchange. Build an understanding of the communities' obligations (eg. Lore and sorry business)
- Consider employing research assistants or community navigators in each community you work with. Think about how this employment can be sustained long-term, or beyond the life of the project
- Respect and be guided by the community and their local community protocols. If required, use language translators for written and verbal communication
- Give clear information about the research, using language and formats suitable to the audience
- Give people time to think about the research before being asked to consent. For community research, best practice suggests visiting several times before asking the Community Council or community members to consent. This allows you to build awareness, give people time to get to know the research team and build trust

5.3 Undertake relevant training

It is of critical importance for the research team to be fully informed about the community you will be working with

- When going to a community, check in with the community and Elders. You may be asked to attend a welcoming. This is the best opportunity to build your relationship, and it is considered disrespectful to not attend if invited. If a ceremony is conducted for the research team, ensure you ask if the Elder conducting the ceremony would like renumeration (eg. Honorarium)
- Researchers must complete local cultural awareness training prior to visiting community. Ask the community representatives if they have a course, they will prefer you take or speak to Kulunga for advice
- Ensure all members of the team are provided with relevant training. Examples of training can be found in the checklist and or speak to Research Governance about specifics for your project.
- Researchers should look for elements of the protocol which community can assist with and upskill local community members to complete those parts of the study
- Keep Aboriginal and Torres Strait Islander people involved in the research throughout the life of the project
- Inform community how they can report concerns or safety issues, and that they have the right to withdraw from research at any time

Standard 6 Analysis and Reporting

6.1 Analyse results together

Aboriginal and Torres Strait Islander people and communities must be involved in the analysis, interpretation and reporting

- This may be through existing governance structures, ongoing community engagement or other processes, depending on the nature of the research
- Aboriginal and Torres Strait Islander history, culture and world views are not homogenous. Ensure the results are disaggregated and presented with strengths-based narratives
- Colonisation and subsequent intergenerational trauma still affect Aboriginal and Torres Strait Islander people. Consider how these experiences contribute to and influence the findings of the study

6.2 Report back to community and stakeholders (stay connected)

Before publication of findings, participating Aboriginal and Torres Strait Islander communities, stakeholders and/or project governance must have an opportunity to review results and provide feedback

- Community and stakeholders must be given the opportunity to request edits to ensure findings are valid, respectfully presented, to correct cultural inaccuracies, protect traditional knowledge, and assess for potential risks to the community. They may also wish to provide their expertise on the best methods and languages for dissemination
- This could include Community Councils and Aboriginal and Torres Strait Islander external organisations or may be through existing governance structures, ongoing community engagement or other processes
- Develop community activities to engage community and recognise and thank them for their contribution. For example, a community barbecue or movie night
- Develop plain language summaries for communities, or other ways of presenting information that communities have requested or agreed to, alongside scientific outputs
- Ascertain who wishes to be acknowledged and identified

6.3 Proper acknowledgement and recognition

Publications should acknowledge the contribution of Aboriginal and Torres Strait Islander communities and people as appropriate:

- For clarity, simply ask how contributors wish to be acknowledged
- If including any Indigenous Cultural and Intellectual Property (ICIP) in written publications, ensure prior permission has been sought to include such ICIP and all cultural protocols for such inclusion are met - as well as ensuring copyright and authorship of such publications appropriately reflect such contributions
- Speak to Kulunga and/or refer to the Institute's Authorship policy for guidance about community inclusion in authorship
- Where ever possible, co-present with an Aboriginal and Torres Strait Islander staff member, co-researcher or community member

Standard 7 Translation

7.1 Share findings in a way that is relevant to communities

Research results and outcomes are co-designed with and shared with the Aboriginal and Torres Strait Islander people, communities and stakeholders who were involved in the research

- Ask Aboriginal and Torres Strait Islander people and communities involved in the research how they would like the findings and data presented. Co-design research outputs with them
- Publish and broadcast findings widely, including other Aboriginal and Torres Strait Islander communities, state or national Aboriginal community-controlled organisations, that will benefit from the findings
- When presenting to community or media, include local members and stakeholders who have contributed to the project
- Work with the Communications and Kulunga teams to develop a communications strategy, develop contingencies to protect the findings from misinterpretation and exploitation. Misinterpretation of the findings that leads to bad publicity can be very damaging for communities
- Get advice from Kulunga on your publications and media releases to ensure where relevant they are strength based.

7.2 Explore other translation opportunities (eg. co-authorship, co-conference presentations, and health promotion)

Next steps are discussed with Aboriginal and Torres Strait Islander people, communities and stakeholders who were involved in the research and clear actions are taken to translate findings into change in policy and practice in participating communities, at a local, state and national level as necessary

- Revise your translation finding and act on it. Ensure you utilise a strengths-based approach
- Find ways to ensure the study's health message and findings are returned in a way that is useful for the community and self-sustaining. For example, create story books that can be shared in schools or work with health centres to get the message embedded into onboarding material for new staff members
- Even though the project may have finished, discuss with the community and external stakeholders what are the next translation steps needed to create the health improvements they are seeking. What is needed to create the health and wellbeing improvements?
- Stay connected with the people and communities you have built relationships with. Ask them how they would like you to translate your research
- Speak with the Government Relations team and explore if they can help facilitate connections with government stakeholders to drive advocacy for meaningful changes in policy and practice
- Make sure that knowledge translation is expanded across to communities that will benefit and receive impact from findings
- Partner with communities to use findings to influence changes to policy and practice

7.3 Consider how to deliver impact in partnership with community through advocacy and alignment to government policies

- Consider if your research could be used to support or influence government policies and services (eg. Closing the Gap)
- Talk to the Government Relations team about existing connections to government and community that could be pathway to translation and impact
- Explore with your community partners whether they are already working with government to improve systems and policies and how your research might help with those efforts
- Offer to partner with community to advocate to government. The Government Relations team can support you with that

Standard 8 Evaluation

8.1 Research project close out

- Researchers have closed off the databases and archived all data (and biosamples, if applicable) in line with the project's Data Management Plan (and biosample management procedures, if applicable)
- The project's findings have been shared with Aboriginal and Torres Strait Islander people and communities in line with the results dissemination plan
- Researchers have completed all final reports for the project and finalised the study's ethics and governance

8.2 What is the benefit for communities on the ground?

- Share the outcome of research; be transparent about the opportunities and challenges
- Research is a two-way learning journey, reflect on what you have learnt from community and how it has improved your research practices
- Advise communities of the next steps
- Will the outcome of your project be used in advocacy of policy and/or service delivery changes in collaboration with the community

8.3 Has the research met desired results?

- Did the research answer the community's research questions?
- Did the research identify further research opportunities?
- Did the research meet community expectations and was the community happy with the outcomes?
- Ensure you include reflective practice within the team

8.4 Learning from research and planning next steps – knowledge translation

Reflect and evaluate the research process for the project and, with participating communities and organisations, discuss what worked and what didn't and what is needed next.

- Use the Standards document and checklists, as well as other resources to conduct honest forensics review of the project as a means of improving future projects
- Share your evaluation with Kulunga and your colleagues at the Institute. For example, you could present to the Institute's Aboriginal Community of Practice group
- Include a formal wrap-up and learning workshop with Aboriginal and Torres Strait Islander community partners. Be sure to share how findings will be useful to Aboriginal and Torres Strait Islander community partnerships
- Consider publishing your summary for a broader audience

The Standards training

The Aboriginal and Torres Strait Islander Research Standards is embedded within the Institute through training to enable best practice for researchers and teams when working with our community. Over the last two years staff have provided valuable feedback on the training. Below are quotes from representatives across the Institute:

They provide a really clear pathway to follow to ensure best practice in working with Aboriginal individuals and communities (and arguably all communities).

The scope of the standards and the process of consultation. I like the requirement that research involving Aboriginal communities must show how the work will benefit the community.

I think reciprocity is the main take away for me and always considering what are the priorities of the communities

It has given me greater respect and appreciation for the need to work with community and how important it is to take the time to do it right in the best interests of community (not the research)

It's been a great way to refocus my perspective to make sure everything I do as a researcher is prioritising Aboriginal voices, and it's given me a good idea of who to reach out to for support when I need it.

A deeper understanding, especially around reciprocity and the aspects of time.

For me, it really helps set the scene on how the Institute prioritises working with Aboriginal community and placed-base research. It allows me to have a background for when I speak externally to partners and find ways of research collaboration.

It has definitely opened my eyes how we engage, acknowledge and include Indigenous communities in our research. Not just in the middle, or the end of the process, but from the outset.

Resources and support

Thank you for your interest in The Standards. This is the start of deepening your understanding of working with Aboriginal and Torres Strait Islander communities and peoples. The Kulunga team, along with other teams at the Institute, is here to guide and support you. Below you will find the ways we can guide you and some additional reading to support you.

Seek advice from Kulunga Aboriginal Unit to:

- Be the first point of contact for Research teams
- Help identify candidates to assist with recruitment of Aboriginal and Torres Strait Islander staff
- Provide advice on setting up a Community Reference group
- Schedule a presentation to the Aboriginal Research Projects Forum for feedback (convened by Kulunga)
- Identify and meet with key local Aboriginal and Torres Strait Islander people, communities, including Elders and external organisations preferably Aboriginal and Torres Strait Islander
- Identify if there have been any Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander researchers who have experience in your field
- Assist with linking Aboriginal and Torres Strait Islander researchers to relevant research projects
- Facilitate consultation with Aboriginal and Torres Strait Islander communities and organisations including Aboriginal Medical Services, Prescribed Body Corporate
- Make links to local interpreters and translators
- Hold community meetings and get feedback on the analysis
- Continued ongoing support from participating Aboriginal Medical Services, community councils, organisations, and members
- Provide assistance with IP, ICIP and data sovereignty
- Provide advice on other teams in the Institute who can assist you with your project
- Help with meeting the ethics letter of support process
- Provide advice and guidance on art procurement and honorarium process

KULUNGA Team:

Kulunga@thekids.org.au

Attend:

- Cultural Awareness training to inform and build understanding of how Aboriginal and Torres Strait Islander history of colonisation and State control of Aboriginal and Torres Strait Islander people impacts research
- Relevant PD, conferences and Aboriginal and Torres Strait Islander methodology course
- Good clinical practice training
- Undertake relevant Community Researcher training
- Standards training

Seek input and advice:

- From other Institute research projects about models of leadership, decision-making and accountability
- Speak to the Contracts team at the Institute for advice on navigating relevant agreements
- Speak to Research Governance at the Institute for advice on ethics and governance processes including purchase of art works
- From Aboriginal and Torres Strait Islander people or community about what has been done to address the issue of interest in the past, what has worked, what has not and why
- From Education Department in regard to your research if you propose to work in schools

Checklists:

Checklists for each of the Standards provide guidance around the questions and considerations you should be thinking about when implementing the Standards in your research.

https://telethonkids.sharepoint.com/sites/telescope-working-at-the-institute/SitePages/Working-with-Aboriginal-Communities.aspx

National Peak Aboriginal and Torres Strait Islander research and ethics organisations:

Western Australian Aboriginal Health Ethics Committee
https://www.ahcwa.org.au/sector-support/waahec/

Aboriginal Health Council SA
https://ahcsa.org.au/

Victorian Aboriginal Community Controlled Health Organisation
https://www.vaccho.org.au/

Aboriginal Health and Medical Research Council of NSW
https://www.ahmrc.org.au/

Queensland Aboriginal Islander Health Council
https://www.qaihc.com.au/

Aboriginal Medical Services Alliance Northern Territory
https://www.amsant.org.au/

OCHRe Network
https://www.ochrenetwork.org/

Links and further reading:

NHMRC National Statement on Ethical Conduct in Human Research (2025)
https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2025

NHMRC Aboriginal and Torres Islander Health
https://www.nhmrc.gov.au/health-advice/aboriginal-and-torres-strait-islander-health

National Health and Medical Research Council, 2018, Ethical Conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders, Commonwealth of Australia, Canberra (NHMRC Guidelines 2018) at page 2
https://www.nhmrc.gov.au/about-us/publications/ethical-conduct-research-aboriginal-and-torres-strait-islander-peoples-and-communities

National Health and Medical Research Council, 2018, Keeping Research on Track II, Commonwealth of Australia, Canberra
https://www.nhmrc.gov.au/about-us/publications/keeping-research-track-ii

AIATSIS
https://aiatsis.gov.au/research/ethical-research/code-ethics

Lowitja Institute
https://www.lowitja.org.au/

Lowitja self assessment tool
https://www.lowitja.org.au/tools/indigenous-data-sovereignty-readiness-assessment-and-evaluation-toolkit/

Taking Control of Our Data. A Discussion Paper on Indigenous Data Governance for Aboriginal and Torres Strait Islander People and Communities January 2024
https://www.lowitja.org.au/wp-content/uploads/2024/01/Taking-Control-of-Our-Data-Discussion-Paper.pdf

Laycock A. with Walker, D, Harrison, N & Brands, J, 2011, Researching Indigenous Health: A Practical Guide for Researchers, The Lowitja Institute, Melbourne (Lowitja Institute Guide) at page 42
https://www.lowitja.org.au/resource/researching-indigenous-health-guide/

Maiam Nayri Wingara
https://www.maiamnayriwingara.org/

Carroll, S, et al. 2020. The CARE Principles for Indigenous Data Governance. Data Science Journal, 19: XX, pp. 1–12.DOI: https://doi.org/10.5334/dsj-2020-042

Indigenous Data Sovereignty, Communique, Indigenous Data Sovereignty Summit, 20th June 2018, Canberra, ACT
https://static1.squarespace.com/static/5b3043afb40b9d20411f3512/t/63ed934fe861fa061ebb9202/1676514134724/Communique-Indigenous-Data-Sovereignty-Summit.pdf

Trudgett et al. 2022. A framework for operationalising Aboriginal and Torres Strait Islander data sovereignty in Australia: Results of a systematic literature review of published studies. eClinicalMedicine 2022;45: 101302, Published online 17 February 2022, https://doi.org/10.1016/j.eclinm.2022.101302

Indigenous Data Governance Communique National Indigenous Data Sovereignty Summit 13th June 2023, Cairns, QLD
https://www.maiamnayriwingara.org/2023-summit

Terri Janke and Company, Indigenous Health Genomics: The legal, ethical and social issues, 2020
https://www.health.gov.au/sites/default/files/documents/2022/11/indigenous-health-genomics-the-legal-ethical-and-social-issues.pdf

Closing the Gap
https://www.closingthegap.gov.au/

Closing the Gap report 2022
https://humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/close-gap-2022

Uluru statement from the heart
https://ulurustatement.org/the-statement/

Bringing them home report recommendations
https://bth.humanrights.gov.au/the-report/report-recommendations

Securing Our Rights, Securing Our Future Report
https://humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/wiyi-yani-u-thangani

UN Declaration on the Rights of Indigenous Peoples
https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf

HealthInfoNet
https://healthinfonet.ecu.edu.au/

Australian Indigenous Doctors Associations
https://aida.org.au/

Indigenous Allied Health Australia
https://iaha.com.au/

Congress of Aboriginal Torres Strait Islander Nurses and Midwives
https://catsinam.org.au/

National Aboriginal Community Controlled Health Organisation
https://www.naccho.org.au/

National Aboriginal and Torres Strait Islander Health Workers and Health Practitioners
https://www.naatsihwp.org.au/

The Kids Research Reimagined Strategic Plan
https://www.thekids.org.au/about-us/vision-and-strategy/

The Kids Innovate Reconciliation Action Plan
https://www.thekids.org.au/RAP

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Notes

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