



Guidelines for the  
**Standards for the Conduct of  
Aboriginal Health Research**

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## Acknowledgement

Telethon Kids Institute 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 Kurna 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.

# ABOUT THE GUIDELINES

At Telethon Kids Institute, Aboriginal Health is everyone's business. It is an expectation that research projects consider the needs of Aboriginal children and families in all the work they do.

In our strategic plan "Up for the Challenge" we undertake to prioritise our partnerships with Aboriginal families and communities to improve the health and development of Aboriginal children and promise that "we will not ignore, nor accept, the continued disparity in outcomes for Aboriginal Kids compared with other Australians."

How we go about that is set out in our Commitment to Aboriginal Children and Families. The Institute's Standards for the Conduct of Aboriginal Health outline our way of working with Aboriginal communities and peoples to make sure we can deliver on that promise.

This Guideline is designed to help Institute staff to understand what actions and activities they must take throughout their research projects to meet the best practice expectations outlined by both the Institute and the National Health and Medical Research Council (NHMRC).

Working in genuine partnership with Aboriginal peoples and communities, and other relevant stakeholders, to deliver great outcomes is a different way of working to what some may be used to.

It requires us to listen and respond to the community's priorities, to respect Aboriginal governance, to build community capacity and foster relationships that may extend way beyond a project's life.

When done well, the outcomes can be transformative -- for the community and for us all.

We hope you find this a useful resource. The Kulunga Aboriginal Unit looks forward to supporting you through this journey.

Please reach out to ask questions and build your knowledge on your research journey.

### Citation:

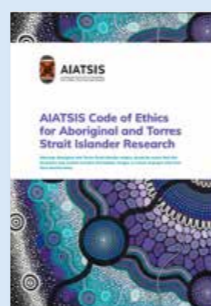
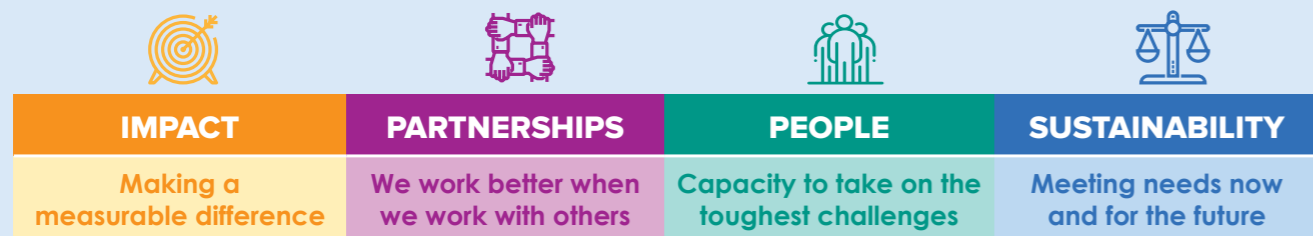
Telethon Kids Institute. (2022). *Guidelines for the Standards for the Conduct of Aboriginal Health Research*. <https://www.telethonkids.org.au/globalassets/media/documents/aboriginal-standards-guidelines---july-2022.pdf>

# INTRODUCTION

The Telethon Kids Institute has developed its Standards for the Conduct of Aboriginal Health Research consistent with its Strategic Pillars and Commitment to Aboriginal Children and Families. They are also aligned with best practice advice from the NHMRC and the Australia Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS).

## STRATEGIC PILLARS

Four strategic pillars are the foundation for delivery of our mission:



The best practice advice from the NHMRC are the '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 *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities*). The AIATSIS best practice advice is the 'Code of Ethics for Aboriginal and Torres Strait Islander Research'.

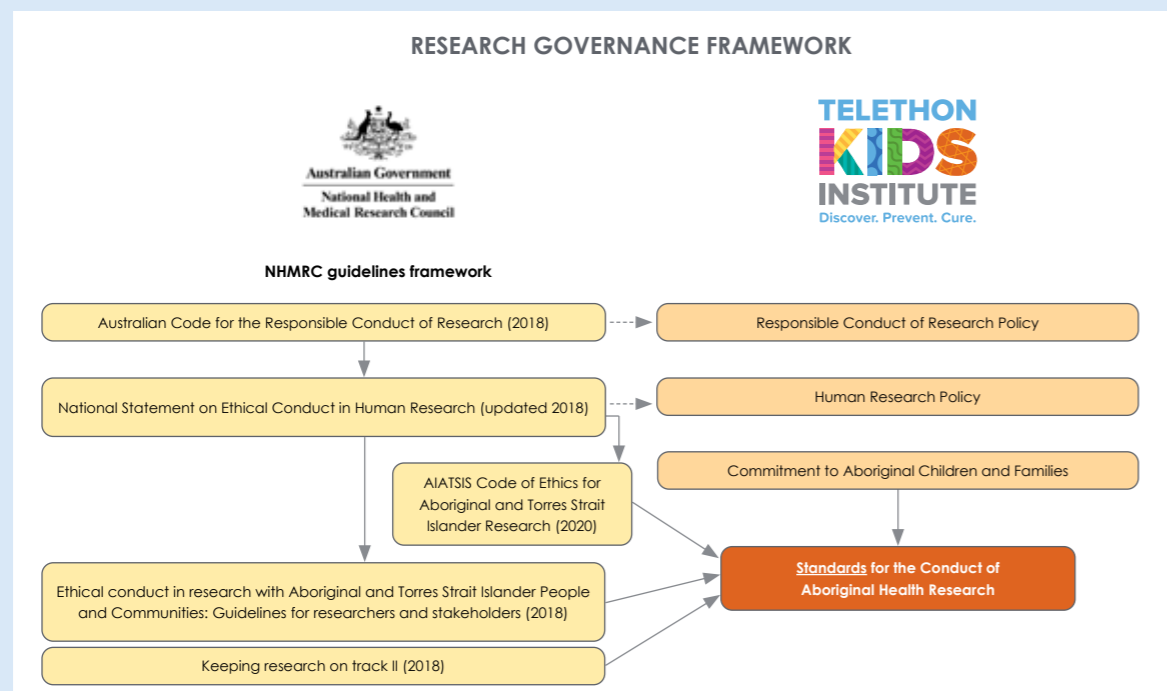


Figure 1 | NHMRC guidelines, AIATSIS and Telethon Kids Institute frameworks

# PURPOSE OF THE STANDARDS

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

The Aboriginal Research Standards have been developed to guide and support Institute Research teams and other staff to work towards achieving best practice in Aboriginal health research.

# ETHOS OF THE STANDARDS

The Institute uses a strengths-based approach in its work with Aboriginal and Torres Strait Islander Peoples and communities. This means understanding that people and communities have strengths from their experiences that give them knowledge and insights into addressing health and other issues in their community(ies).

Research teams with the help of the Kulunga Aboriginal Unit, and their Aboriginal community engagement or liaison specialist team member(s) (if applicable), must consider and work with the strengths and capabilities in communities that they can leverage for their intended research project.

# WHO DO THE STANDARDS APPLY TO?

The Aboriginal Research Standards apply to any investigator seeking to engage in research relating to Aboriginal children, youth and families. This includes research where Aboriginal children are the primary focus or where they are a subset of a larger population, whether the research is conducted in communities or with existing and/or historical data and/or biological samples.



# THE STANDARDS

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

The Aboriginal 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 Research Standards process

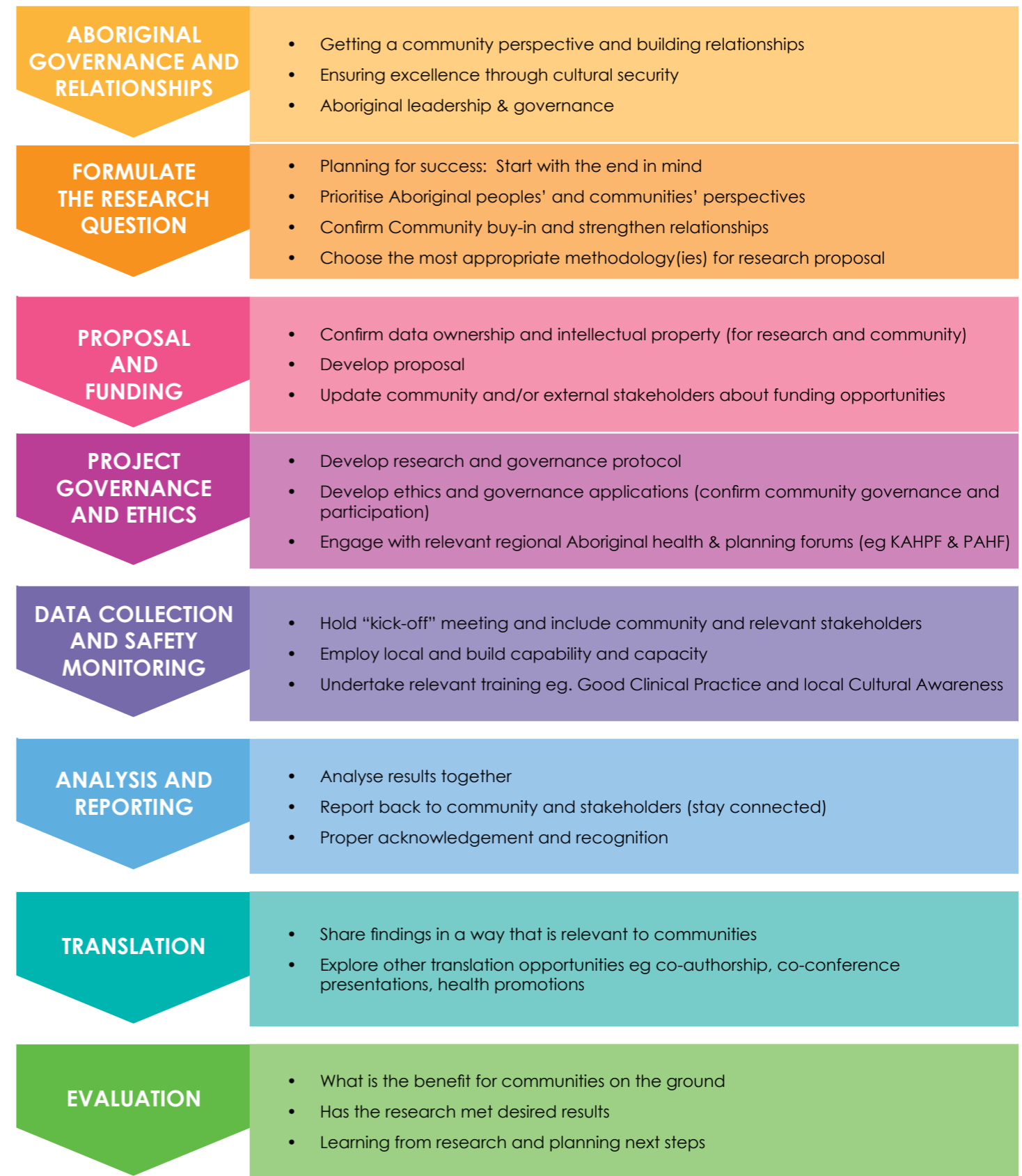


Figure 3 | Aboriginal Research Standards and subsequent Actions

# RELATIONSHIPS

Many of the principles, and indeed Standard 1 – Building Relationships, are relevant to forming and maintaining genuine relationships with Aboriginal communities and people which require ongoing contact. Contact and consultation cannot be purely transactional or one-sided that serves only the Institute's immediate or short term goals.

Community members who participate in research projects often forge deep relationships with research teams especially for multi-year projects with frequent site visits and engagements. A research team and its members can be disingenuous to only want a relationship with community members on the Institute's terms, and just for the length of their research project. Aboriginal communities and peoples have many instances, from decades of experience, where researchers have realised their more direct benefits (say for example research project objectives, published articles, conference papers, academic progress) but the communities' (mostly indirect) benefits are never realised as they are tied and dependent on big systemic changes in areas such as health, education and environmental health.

In their 'Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities' the National Health and Medical Research Council (NHMRC) describes the six core values that are important to all Aboriginal and Torres Strait Islander Peoples. The values ensure all human research undertaken with Aboriginal and Torres Strait Islander people and communities:

- ▶ **Respects** the shared values of Aboriginal and Torres Strait Islander Peoples
- ▶ Is **relevant** for Aboriginal and Torres Strait Islander priorities, needs and aspirations
- ▶ **Develops long-term ethical relationships** among researchers, institutions and sponsors
- ▶ **Develops best practice** ethical standards of research.

The six values are Spirit and Integrity, Cultural continuity, Equity, Reciprocity, Respect, and Responsibility. ['Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities'](#) guidelines document provides further detail.



Figure 4 | Six core values of Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities.

Source: NHMRC Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders

## What the community has told us

The Institute's values of Collaboration and Respect, as articulated in the Up for the Challenge Strategic Plan (2019-2023), 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).

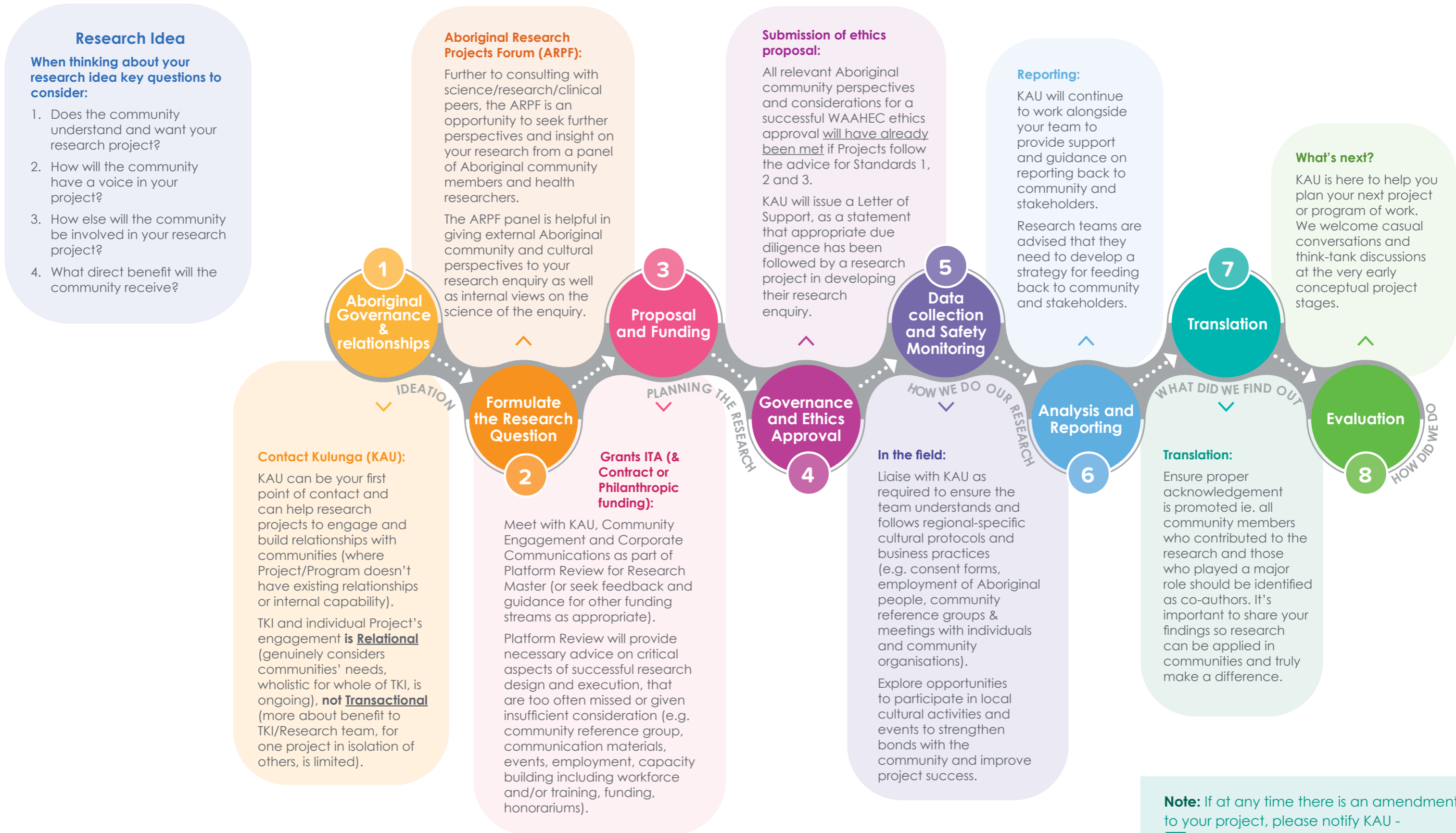
The Standards are also imbued with some critical principles. The principles below are taken from the Kimberley Aboriginal Child and Family Health Research Forum (September 2016) which shows the consistencies between Aboriginal communities and the Institute. The Forum had representation from Aboriginal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

# ABORIGINAL RESEARCH STANDARDS PROCESS

This process diagram is guide for research teams to follow to be consistent with the Aboriginal Research Standards in accordance with the Guidelines. It is recognised the stages in a research project are never linear and all projects will follow different pathways based on the type of project and funding. However, at the forefront of all projects must be continuous Aboriginal community engagement and building relationships throughout the whole project life cycle.



**Note:** If at any time there is an amendment to your project, please notify KAU - [Kulunga@telethonkids.org.au](mailto:Kulunga@telethonkids.org.au)

## Standard 1:

# Aboriginal Governance and Relationships

## 1.1

### Getting a community perspective and building relationships

**Researchers and their teams engage early with Aboriginal peoples, communities and organisations, before developing the research question and design, and continue to regularly engage throughout the project. Be clear about why you are wanting to do this study and who will benefit from the study. To ensure the research will have meaningful benefit to Aboriginal communities, talk to Aboriginal people right from the start.**

- Meet with the Kulunga team who will guide researchers to discuss your ideas with communities
- Use the existing community relationships within your project team to test the applicability and veracity of the research idea. Consider conducting formative research first to understand qualitatively what an issue means to Aboriginal people if it has not already been done
- Conduct a literature review of previous related research and review grey literature and oral histories to understand what has worked, what has not and why. Collaborate with other Institute research teams who may be already working in this area to reduce burden on the community
- Learn some local context to community(ies) where you are thinking about doing a project (eg. local groups, some local history) and the communities' past experience of research
- Understand that there is rarely ever one perspective in community and therefore, you will need to listen to and consider several perspectives on an issue

## 1.2

### Ensuring excellence through cultural security

**Researchers and their teams have the expertise, self-awareness and cultural understanding to conduct respectful research and build strong lasting relationships with Aboriginal people and communities.**

- How will you identify, understand and navigate cultural protocols, norms and dynamics in the Aboriginal community(ies). Kulunga can help you with this
- Work with Kulunga and the local community to ensure the research activity is culturally-safe for community researchers, participants, Elders and others
- Employ Aboriginal people on your project (eg. researchers, community researchers, other project staff)
- Grow your understanding of Indigenous research methodology and review relevant NHMRC guidelines and enhance your understanding in Indigenous research methodologies
- Understand the diversity of Aboriginal peoples, culture, and context and acknowledge the ongoing impact of colonisation, government policies and racism

## 1.3

### Aboriginal leadership and governance

**Project governance has strong Aboriginal leadership and effective accountability to Aboriginal peoples and communities.**

- Ensure Aboriginal researchers are leading the research or included as Principal Investigators, or part of the team
- Where it is appropriate, ensure agreements and clear documentation between Institute researchers and Aboriginal organisations and communities. You may need a research agreement, contract or Memorandum of Understanding (MOU) with an Aboriginal community organisation(s) for this project

**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.**

# Formulate the research question

## 2.1

### Prioritise Aboriginal peoples' communities' perspectives

**Research idea and question is established based on the health and wellbeing priority issues identified by Aboriginal people and communities in consultation with the organisation**

- ▶ Utilise past consultations, previous research or literature reviews, or hold roundtables or workshops, to identify priorities
- ▶ Be aware that National, State and Regional priorities may not automatically align with Communities' priorities. How have you identified, or been informed, about community priorities?
- ▶ Social determinants of health, housing and infrastructure can play a more primary role in people's lives. Does your research topic acknowledge and address these interactions?

## 2.2

### Planning for success: Start with the end in mind

**Researchers have considered in their planning how the result will inform better health and wellbeing outcomes for Aboriginal peoples and communities beyond the life of the project**

- ▶ Clearly state what success looks like. Clearly identify the specific outcomes and deliverables
- ▶ Budgets should include capacity for increasing understanding of Aboriginal families about health issues through culturally appropriate and accessible information and activities, sharing research results etc by regular reporting back to Aboriginal community partners
- ▶ Be open and transparent about who will benefit from the research now and who will benefit from the research into the future

## 2.3

### Confirm community buy in and strengthen relationships

**Researcher continues to engage with Aboriginal peoples, communities and organisations, during the planning and design of the research project to ensure tangible benefits to the Aboriginal communities.**

- ▶ Be clear about the stage of the research and the process for it to go ahead. Seek approvals and funding
- ▶ Check research project will result in direct net benefit for the Aboriginal people and researchers involved in the research i.e. the benefit outweighs the risks/ inconvenience of being involved
- ▶ Benefit should be negotiated with, and understood, as defined by Aboriginal people and/or the community

## 2.4

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

**Researchers need to select culturally respectful methods, balancing scientific rigour, reality and the ethical imperative to respond. Where working in community, methods should be informed by community consultation, negotiation and informed consent.**

- ▶ Negotiate and determine methods together with Aboriginal participants, communities/governance
- ▶ Understand power imbalances between the researcher and the participants and implement strategies recommended in the NHMRC's National Statement
- ▶ Use methods that respect cultural ways of working and ensure Aboriginal perspectives are heard and acted upon. For example, consider incorporating more qualitative and participatory methods as well as reciprocity
- ▶ Where working in community, 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 (time, staff including on the ground community staff)





## Proposal and Funding

### 3.1

#### Confirm data ownership and intellectual property (for research and community)

**Researchers recognise and respect the intellectual property rights and proprietary interest of Aboriginal communities and individuals to cultural knowledge systems, data and bio samples generated or collected during research.**

- ▶ Aboriginal peoples have a fundamental and legal right of ownership over their own knowledge and information
- ▶ Aboriginal peoples have a right to free and informed prior consent to participate or withdraw from a research project
- ▶ Intellectual property and future use of samples are discussed and agreed with all participating Aboriginal organisations, community members and/or Aboriginal representatives. Any data collection should not occur before ethics and governance approval
- ▶ Consent forms make it clear who owns the data and how data and samples will be stored and 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 Human Research Ethics Committee and relevant organisations
- ▶ Ensure Aboriginal 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

### 3.2

#### Develop research and funding proposal

**The proposal is of high quality and achieves best practice in Aboriginal Health 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 governance and is culturally relevant, appropriate and safe
- ▶ Having an Aboriginal perspective in the initial draft of your proposal will have far reaching benefits
- ▶ The proposal includes clear articulation of your engagement with and involvement of the community before, during and after the research project
- ▶ The research proposal meets the NHMRC guidelines and Aboriginal Excellence Framework

### 3.3

#### 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**

- ▶ Be clear about funding timelines and update people when details change
- ▶ Agreed benefits should include capacity building and employment, a value on the in-kind and unfunded support you expect from Aboriginal organisations and community members. For example, for time attending meetings, discussing the project, using premises, vehicles etc. Ensure research budgets cover costs such as backfilling positions, using partners' facilities, transport, administration, and interpreters



# Project Governance and Ethics



## 4.1

### Develop research protocol

**Consider the following:**

- ▶ Training and employment of local people and community members (e.g. data collection, consent process, cultural navigation, cultural governance and protocols)
- ▶ Engage the community through the arts where possible (artists, storytellers, interpreters, writers, actors, etc). Refer to the Aboriginal art code as a guide.
- ▶ Remember - the people most equipped to ensure research is undertaken and implemented in a culturally secure way are people from the same community

## 4.2

Engage with relevant regional Aboriginal health & planning forums (eg. Kimberley Aboriginal Health Planning Forum & Pilbara Aboriginal Health Forum)

- ▶ Researchers who actively engage with Aboriginal Planning forums benefit from local input and establish ongoing relationships for the implementation of results and for future research proposals
- ▶ Local health and planning forums are a great source of regional knowledge and strategic priorities



## 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 peoples culture, language and understanding
- ▶ Gain letters of support from relevant Aboriginal communities, region where research will be undertaken, to submit with your ethics application
- ▶ Develop relevant agreements for the protection of participants, their data and samples, as well as data and IP ownership
- ▶ Ethics and governance must be approved before starting the research
- ▶ Establish your Aboriginal Governance for the project such as Community Reference Groups or Advisory Groups

## Standard 5:

# Data Collection and Safety Monitoring

## 5.1

### Hold “kick-off” meeting

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

- › Keep people and communities informed of the progress of the research even when not in community
- › Maintain community relationships and participate in important community events
- › Think about the six core values (eg. Reciprocity) and how you give back to the communities you work within
- › Be clear about your timelines and update people when things change
- › Project teams attendance at local cultural awareness training is imperative

## 5.2

### Employ local, build capability and understand cultural protocols

**Research is conducted with Aboriginal people and in Aboriginal communities in accordance with local cultural protocols, including protocols around reciprocity and knowledge exchange.**

- › Understanding communities' obligations (eg. Lore and sorry business)
- › Respect and be guided by the community and their local community protocols. Use English translators if needed
- › 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 (eg. Good Clinical Practice and local Cultural Awareness)

**The importance of the research team to fully informed about the community you will be working in.**

- › 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 considered disrespectful to not attend if invited
- › Ensure Aboriginal members of the team are provided with training in good clinical practice and safety monitoring
- › Keep Aboriginal people involved in the research, how they can report concerns, safety issues and have the right to withdraw from research at any time



## Analysis and Reporting

### 6.1

#### Analyse results together

**Aboriginal people and communities must be involved in the analysis and interpretation**

- ▶ This may be through existing governance structures, ongoing community engagement or other processes, depending on the nature of the research

### 6.2

#### Report back to community and stakeholders (stay connected)

**Before publishing the report, participating Aboriginal communities, stakeholders and/or project governance must have an opportunity to review results and provide feedback**

- ▶ This may include requests for 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 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 bbq or movie night

### 6.3

#### Proper acknowledgement and recognition

**Publications should acknowledge the contribution of Aboriginal communities and people as appropriate, unless participants explicitly not wish to be identified or acknowledged**

- ▶ For clarity, simply ask how contributors who wish to be acknowledged
- ▶ Authorship considerations



## Standard 7:

# Translation

## 7.1

### Share findings in a way that is relevant to communities

**Research results and outcomes are shared with the Aboriginal people, communities and stakeholders who were involved in the research**

- ▶ Ask Aboriginal people and communities involved in the research how they would like the findings and data presented
- ▶ Publish and broadcast findings widely, including other Aboriginal communities that will benefit from the findings
- ▶ When presenting to community or media, include local members and stakeholders who have contributed to the project

## 7.2

### Explore other translation opportunities (eg. co-authorship, co-conference presentations, health promotions)

**Next steps are discussed with Aboriginal 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
- ▶ Even though the project may have finished, what is the next step needed to create the health improvements you were seeking
- ▶ Stay connected with the people and communities you have built relationships with. Ask them how they would like you to translate your research
- ▶ Make sure that knowledge translation is expanded across to communities that will benefit and impact from findings
- ▶ Partner with communities to use findings to influence changes to policy and practice



## Standard 8:

# Evaluation

### 8.1

What is the benefit for communities on the ground

- ▶ Share the outcome of research; be transparent of the strengths and weakness
- ▶ Advise communities of the next steps
- ▶ Will the outcome of your project be used in advocacy of policy and or service delivery changes

### 8.2

Has the research met desired results

- ▶ Did the research answer the research question and also did it identify further research opportunities
- ▶ Have you considered how to include reflective practice within the team

### 8.3

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.**

- ▶ Conduct honest forensics review of the project as a means of improving future projects
- ▶ Share your evaluation with your colleagues at the institute
- ▶ Include a formal wrap-up and learning workshop with Aboriginal community partners. Be sure to share how findings will be useful to Aboriginal community partnerships.
- ▶ Consider publishing your summary for a broader audience



# THE STANDARDS IN ACTION

There are many researchers at the Institute already demonstrating the Aboriginal Research Standards in their research projects and in the ways they work with Aboriginal communities and peoples. Here we highlight a few, more are featured in training and other resources.

"Because our history with research hasn't always been positive, now having community involved in our research and having a voice at the table, that two way learning happens all the time. So Aboriginal communities and families are knowing now what research really is, why it's important and how it can be helpful and they're really happy to be part of that now, where as in the past it wasn't always like that."

**Val Swift, Djaalinj Waakinj Aboriginal ear health program**



"Building relationships is essential, its core to doing research in this area. I spent a few years trying to get things done and got nothing done – I really struggled and I found it impossible to get started – until John Jacky (from Kulunga) came along. John could make introductions, and with those introductions, conversations were started.

As a local, well-respected person, John could decide who I needed to be introduced to, introduce me and vouch for me as well. Firstly, I had to build a relationship with John so he knew who I was, who he was introducing to his friends, colleagues, Elders and the communities in which he lived. People need to know you and be comfortable with you and what you're trying to do.

For me – a South African now calling Australia my home – I didn't understand the Aboriginal culture very well and I had to learn and you learn this best from Aboriginal people. John really guided me in this area and he taught me how to go about doing research with Aboriginal people. I also received advice and guidance from research colleagues like Roz Walker who had many years of experience working with Aboriginal communities, and local Aboriginal nurse Mary Lane gave me cultural advice that has proven invaluable in my research.

As a clinician, I had professional relationships with patients and families but for our research to be a success, I had to partner with service providers like local Aboriginal Medical Services. Again, it was John who introduced me to the CEO's of those Aboriginal Medical Services. Once we had those introductions through John, and once we had conversations and people got to know you, they were really interested.

John also taught my team and I to nurture those relationships. You can't go into a community, have a conversation, get a form signed and seeya later. We had to be in touch regularly, give feedback and updates about where we were going and what we were doing. That might sound like a hassle but it's actually very good because if you have that back and forth, you get more of a partnership happening. We would give an update, we would get feedback from community, we would then finetune things based on that feedback for the next visit."

**Associate Professor André Schultz, Wet cough study**



"The Elders feel very honoured that they are working as honorary researchers for Telethon Kids Institute. They're very passionate about the three areas for which they are advocating on behalf of the community. As Honorary Elder Researcher Auntie Millie says "I walk in two worlds between research and urban traditional life representing the voices of my community in striving to improve the health and wellbeing of our children and families. Aboriginal people need to be included and acknowledged by research as we work together to improve health and wellbeing for all people within Western Australia. Any research involving our communities also needs to be undertaken in true partnership with Aboriginal people. This includes strong Elder-led governance, Aboriginal people consulting on research funding applications and genuine community consultation to allow us to walk alongside each other as we determine our own health needs, wishes and treatments." So our Elders see the Institute as an avenue for them to do that - they do feel that they have a voice - and I think that is in essence what they feel the Institute has given them. They are all big advocates on walking this together- you offer us something as researchers and we offer you an insight and the privilege to walk beside us within our communities. But you can't do that without us, they're very strong in that you can't, and you shouldn't be doing that without us. So they see that this partnership is really strong and important."

**Carol Michie, Ngulluk Koolunga Ngulluk Koort Program**



"A lot of Aboriginal people have been negatively impacted in many ways by Western research over time and the way that you rebuild that trust is to actually let the Aboriginal world view and ways of working have priority. Honorary Elder Researcher Uncle Albert is constantly reminding us that we need to work together and that means not just as human beings - no matter what colour we are - but it also means bringing the best of all of our own cultures and sciences and wisdoms together because that's the only way that we're going to be able to solve the many wicked problems that we face. So I think it's really about relationships at the core, we've got to trust and respect each other and trust the process as well. And so I guess that part of my journey is learning to have faith, it'll happen, you've just got to try and not force things."

**Brad Farrant, Ngulluk Koolunga Ngulluk Koort Program**



"I don't think that any team can ever do enough cultural awareness training and I will find funding for my team over and over again to get more of it. Back in 2015/2016, I didn't recognise how important that was and so it wasn't built into any of the funding models. Now, I think from a leader's perspective, the more times that you sit with your team and sit with Aboriginal people doing cultural training, the more we can learn about one another and walk together. It's really important that we get to know one another as well as walk together, and as leaders, we can create the funding, the space, the time and the presence of being there. I don't think leaders should abdicate that responsibility. I think that showing up and being as curious as everyone and creating space for your team to learn is really, really important. I also think that getting to know one another and building relationships is at the heart of it. Taking time to sit down and have a yarn, taking time to go on the trips. Something that's been asked of me over and over again is to keep showing up in community and continuously trying to make sure that we don't operate just from Perth, but we are present in community and showing up as a leader to lead your team through the study and new transitions. As a research leader, I know it might feel a little bit overwhelming at first, but if you're not sure how to navigate it or you don't know how to do something, that's okay, just ask. The Kulunga team has lots of knowledge and there are other researchers who you can ask."

**Associate Professor Asha Bowen, Skin Health team**



# RESOURCES AND SUPPORT

Thank you for your interest in these guidelines. This is the start of deepening your understanding of working with Aboriginal 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 help identify candidates to assist with recruitment of Aboriginal staff
- Provide advice on setting up a Community Reference group
- Consider presenting to the Aboriginal Research Projects Forum for feedback (convened by Kulunga)
- Identify and meet with key local Aboriginal people, communities, including Elders and external organisations preferably Aboriginal
- Identify if there have been any Aboriginal and non-Aboriginal researchers who have experience in your field
- To assist with linking Aboriginal researchers to relevant research projects
- To facilitate consultation with Aboriginal 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
- IP and data sovereignty
- To provide advice on other teams in the Institute who can assist you with your project
- Being the first point of contact for Research teams
- To help with meeting the ethics letter of support process

## KULUNGA Team:



[Kulunga@telethonkids.org.au](mailto:Kulunga@telethonkids.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 people impacts research
- Relevant PD, conferences and Aboriginal methodology course
- Good clinical practice training
- Undertake relevant Community Researcher 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 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



## Links:

- NHMRC National Statement on Ethical Conduct in Human Research (2007) <https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018>
- NHMRC Aboriginal Excellence framework <https://www.nhmrc.gov.au/health-advice/aboriginal-and-torres-strait-islander-health>
- Keeping research on track II <https://www.nhmrc.gov.au/about-us/resources/keeping-research-track-i>:
- AIATSIS <https://aiatsis.gov.au/research/ethical-research/code-ethics>
- HealthInfoNet [www.healthinfonet.edu.au](http://www.healthinfonet.edu.au)
- Lowitja Institute [www.healthinfonet.edu.au](http://www.healthinfonet.edu.au)
- Australian Indigenous Doctors Associations <https://aida.org.au/>
- Australian Allied Health Australia <https://iaha.com.au/>
- Congress of Aboriginal Torres Strait Islander Nurses and Midwives <https://catsinam.org.au/>
- Australian Indigenous Doctors Associations <https://aida.org.au/>
- Australian Allied Health Australia <https://iaha.com.au/>
- Congress of Aboriginal Torres Strait Islander Nurses and Midwives <https://catsinam.org.au/>
- NACCHO <https://www.naccho.org.au/>
- National Aboriginal and Torres Strait Islander Health Workers and Health Practitioners <https://www.naatsihwp.org.au/>
- 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](https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf)

## National Peak Aboriginal research and ethics organisations:

- Western Australian Aboriginal Health Ethics Committee <https://www.ahcwa.org.au/ethics>
- Aboriginal Health Council SA <https://ahcsa.org.au/>
- Victorian Aboriginal Community Controlled Health Organisation <https://www.vaccho.org.au/>
- NSW Aboriginal Health and Medical Research Council <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/>

## Further reading:

- 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>



## REFERENCES

- 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
- 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
- National Health and Medical Research Council, 2018, *Keeping Research on Track II*, Commonwealth of Australia, Canberra
- National Health and Medical Research Council, 2018, *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)*, Commonwealth of Australia, Canberra (National Statement)

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