

Guidelines for the

Standards for the Conduct of Aboriginal Health Research

Changing the Paradigm:

The Aboriginal Research Standards

Cheryl Bridge



## Presenter Disclosure

In the past 24 months, Cheryl Bridge has no relevant financial relationships with the manufacturer(s) of commercial services discussed in this CME activity

I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.



# **Telethon Kids Institute**



Established in 1990, one of the largest & most successful medical research institutes in Australia



Researchers, professional staff and students



Independent not-for-profit organisation with close ties to Perth Children's Hospital



Formal affiliations with UWA, Curtin and ANU and strong collaboration throughout the higher education sector



Total income in 2021



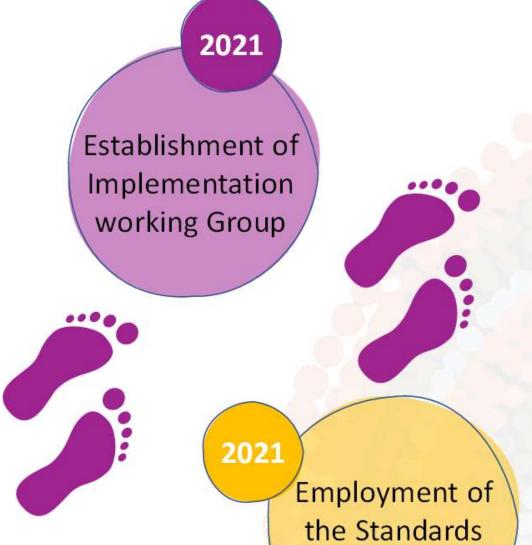
Active research projects

The Journey

2015

Establishment of development working group

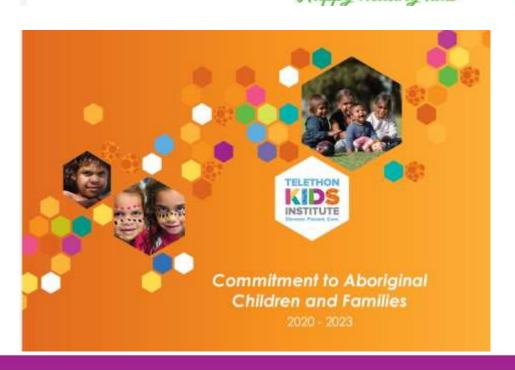




Project Manager

2021 Implementation of The Aboriginal Standards





### STRATEGIC PILLARS

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









IMPACT

Making a

measurable

difference

**PARTNERSHIPS** 

We work better

when we work

with others

Capacity to take on the toughest challenges

**PEOPLE** 

SUSTAINABILITY

Meeting needs now and for the future







#### 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 the community have a voice in your project?
- 3. How else will the community be involved in your research project?
- 4. What direct benefit will the community receive?

#### 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 community members and health researchers.

The ARPF panel is helpful in giving external Aboriginal community and cultural perspectives to your research enquiry as well as internal views on the science of the enquiry.

Proposal and funding

PLANNING

#### Submission of ethics proposal:

All relevant Aboriginal 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.

KAU will issue a Letter of Support, as a statement that appropriate due diligence has been followed by a research project in developing their research enquiry. collection

#### Reporting:

KAU will continue to work alongside your team to provide support and guidance on reporting back to community and stakeholders.

Research teams are advised that they need to develop a strategy for feeding back to community and stakeholders.

#### What's next?

KAU is here to help you plan your next project or program of work. We welcome casual conversations and think-tank discussions at the very early conceptual project stages.

Translation

Evaluation

IDEATO Formulate

Governance and Ethics Approval

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Analysis and Reporting

#### In the field:

MOW WE DO OU

Data

and Safety

Monitoring

Liaise with KAU as required to ensure the team understands and follows regional-specific cultural protocols and business practices (e.g. consent forms, employment of Aboriginal people, community reference groups & meetings with individuals and community organisations).

Explore opportunities to participate in local cultural activities and events to strengthen bonds with the community and improve project success.

WHAT DID WE FIND O

#### Translation:

Ensure proper acknowledgement is promoted ie. 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 in communities and truly make a difference.

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

#### Contact Kulunga (KAU):

KAU can be your first point of contact and can help research projects to engage and build relationships with communities (where Project/Program doesn't have existing relationships or Internal capability).

TKI and individual Project's engagement is Relational (genuinely considers communities' needs. wholistic for whole of TKI, is ongoingl. not Transactional (more about benefit to TKI/Research team, for one project in isolation of others, is limited).

ne Researci Question

Grants ITA (& Contract or Philanthropic funding):

Meet with KAU, Community Enaggement and Corporate Communications as part of Platform Review for Research Master (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 aften missed or given insufficient consideration (e.g. community reference group. communication materials. events, employment, capacity building including workforce and/or training, funding. honorariums).



# **Evidence of Change**

## At Telethon Kids Institute

- Case study of healthy skin presentation aligned with the Standards
- Use of the Kulunga Standards framework by the Community Engagement team
- Requests by teams to deliver the Standards

## **External requests**

- KAHRA ethics application by TKI is the gold standard
- Guest speaker to external organisations CAHS, KAHRA, Planning forums on the Standards

