CAHS Research Education Program Research Skills Seminar

Involving Aboriginal Communities in Research

1st September 2023

Co-presented by

Cheryl Bridge   **Shakara Liddelow-Hunt**

TELETHON
KIDS
INSTITUTE
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A/Prof Bep Uink   MU **Murdoch University**

CAHS Research Education Program Research Skills Seminar Series
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Involving Aboriginal Communities in Research

PRESENTATION SLIDES
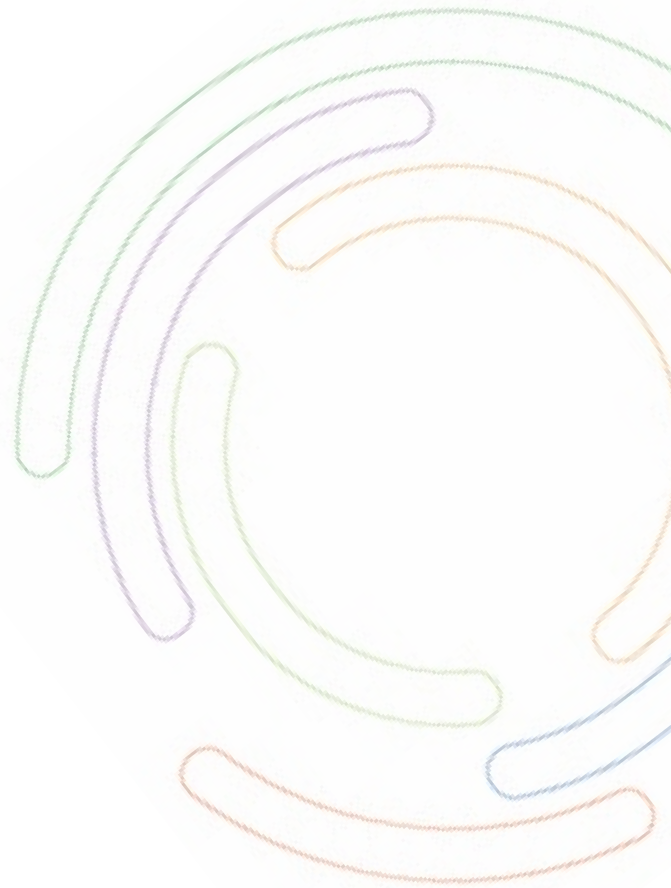
CAHS Research Education Program

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A/Prof Bep Uink

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Acknowledgement of Country

The Child and Adolescent Health Service acknowledge Aboriginal people of the many traditional lands and language groups of Western Australia.
We acknowledge the wisdom of Aboriginal Elders both past and present and pay respect to Aboriginal communities of today.

2

CAHS Research Education Program

Research Skills Seminar Series

A free, open-access resource designed to upskill busy clinical staff and students and improve research quality and impact.

Over 20 topics across the research process
- 1h overview
- Handouts are provided

Recorded and uploaded

Feedback
- Back of handout
- Emailed link

Please hold questions to the end
- Use provided microphone

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Making the health & wellbeing of Aboriginal communities everybody's business at Telethon Kids Institute

Cheryl Bridge – Head, Kulunga Unit

A/Prof Bep Uink - Dean Indigenous Knowledges, Murdoch University

Shakara Liddelow-Hunt - Research Assistant, Youth Mental Health

TELETHON KIDS INSTITUTE
Discover. Prevent. Cure.

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OUR VISION: Happy healthy kids

5

Our Research Focus Themes

Indigenous Health

Brain & Behaviour

Chronic & Severe Diseases

Early Environment

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Indigenous Health Theme - Making the health of Aboriginal children everybody's business

Strategy 1.
- Develop and implement a whole of Institute Aboriginal child and family health research program informed by Aboriginal people and communities

Strategy 2.
- Develop and implement a set of standards for conducting research with Aboriginal families and communities

Strategy 3.
- Develop and implement an Aboriginal Employment and Career Development Strategy

Strategy 4.
- Develop an Aboriginal Communication Strategy that keeps our community connected to us, reflects the diversity of Aboriginal community and challenges the current broken and busted narrative used to describe Aboriginal people

Strategy 5.
- Establish regional platforms to ensure that our research connects to the Aboriginal families we work for and with.
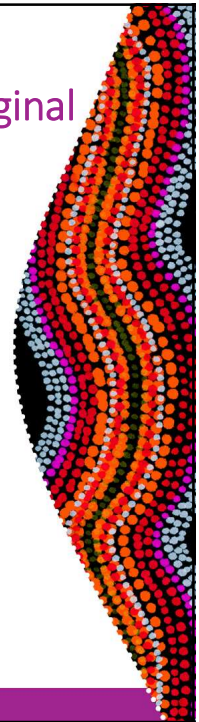
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Indigenous Health Theme - Making the health of Aboriginal children everybody's business

Strategy 2.
- Develop and implement a set of standards for conducting research with Aboriginal families and communities

Strategy 4.
- Develop an Aboriginal Communication Strategy that keeps our community connected to us, reflects the diversity of Aboriginal community and challenges the current broken and busted narrative used to describe Aboriginal people

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The Aboriginal Standards

Guidelines for the
Standards for the Conduct of
Aboriginal Health Research
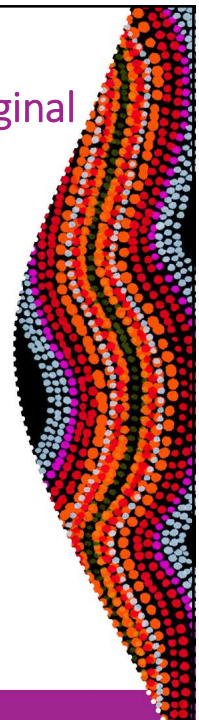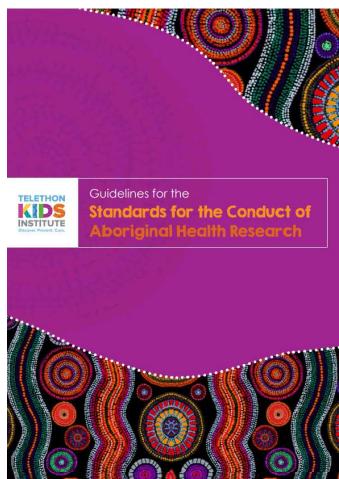
Kulunga values: Respect, Reciprocity, Impact, Accountability, Deep Time

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The Journey so far

2022
Implementation of The Aboriginal Standards

2022
First cohort of Aboriginal Standards Training

2023
Sharing knowledge with external agencies & conferences

2023
Evidence of best practice case studies
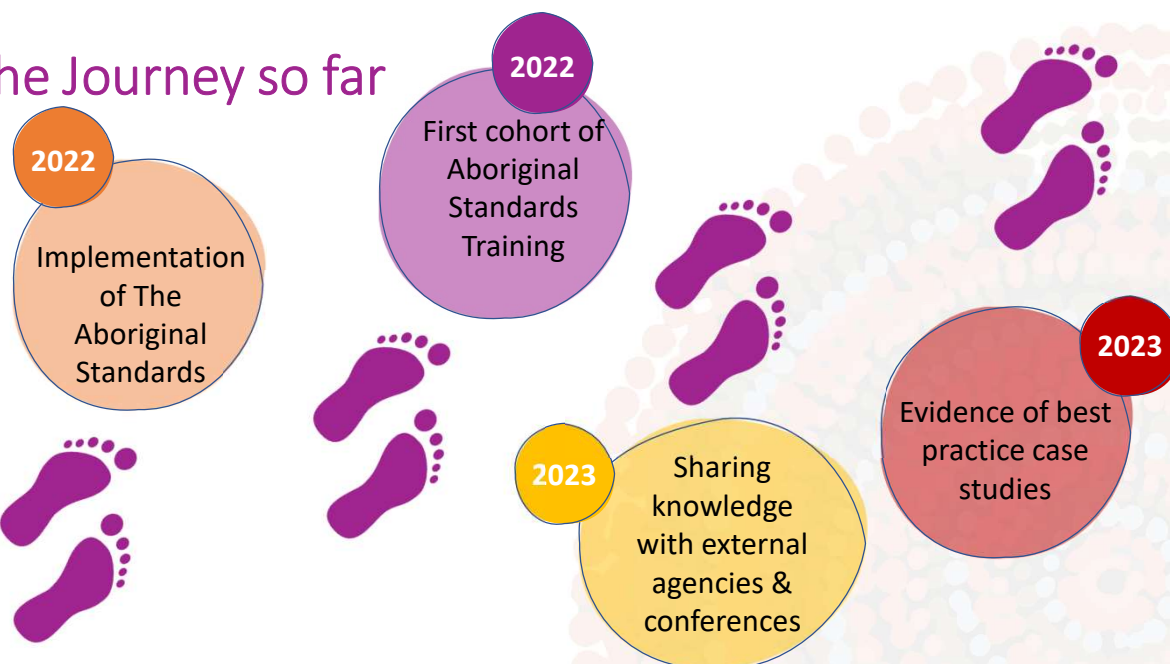
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Impact of the Standards Training - Feedback

"Just thank you, this is really important work and it is so pleasing to see the Institute prioritise this!"

The selection of speakers sharing real examples of the standards in use, makes for understanding the standards easier.

"Give structure, best practice and confidence to our set up of a new project"

"The opportunity to hear first hand the experience of a team that has worked to build relationships and produce an outcome and transition that works for community."

It has increased my knowledge of what it takes to do really good, meaningful, impactful work in an appropriate and ethical way.

Workflow Process

Evidence of Change

Internal

- Case studies and presentations aligned with the Standards
- Use of the Kulunga Standards framework by the TKI Community engagement team
- Requests by multiple teams to deliver the Standards internally
- Fully subscribed participation in the Standards training

External

- Requests by teams to hear about the Standards from Ethics, ACCHO's, WACHS, Universities in WA and over East
- Guest speaker at CAHS, KAHRA, IMICH Conference, Tulsa USA, Communicable Disease Conference, AIATSIS Conf

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Case Study SToP Healthy Skin Books
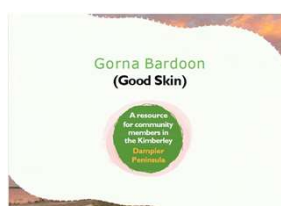
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Walkern Katatdjin (Rainbow Knowledge)

Walkern Katatdjin is a national research project that aims to understand and promote the mental health and wellbeing of Aboriginal and/or Torres Strait Islander Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Asexual (LGBTQA+) young people, and to work with services to develop appropriate interventions.

https://www.rainbowknowledge.org/

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Previous Research

- Theoretically, Aboriginal and Torres Strait Islander LGBTQA+ young people should be at higher risk of negative health outcomes due to intersecting identities because…

- Young, Indigenous, LGBTQA+ each associated with increased risk for: suicide behaviour, psychopathology, distress, homelessness, victimisation, fears around service providers

- Intersectional identity stress

Perspectives

The time for inclusive care for Aboriginal and Torres Strait Islander LGBTQ+ young people is now

Understanding the multiple identity groups of Aboriginal and Torres Strait Islander LGBTQ+ young people can assist in meeting their health care needs

Uink, B., Liddelow-Hunt, S., Daglas, K., & Ducasse, D. (2020). 'The time for inclusive care for Aboriginal and Torres Strait Islander LGBTQ+ young people is now'. *The Medical Journal of Australia*, *213*(5), 201-204.

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Walkern Katatdjin Research Questions

Q1. What impacts the social emotional wellbeing and mental health of Aboriginal and Torres Strait Islander LGBTQA+ young people (14-25 years) in Australia?

Q2. What mental health and social services are youth using?

Q3. What experiences are youth having in mental health services and social services?

Q4. What interventions (if any), and at what level, are needed?

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Questions to ask yourself

What is motivating me?

How did this research question(s) come to me?

Is an Aboriginal and/or Torres Strait Islander person/team already conducting this research?

Can I play a meaningful role in the research team?

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Pre-funding Considerations & Design

- Invitation from community

- Funded through NHMRC Targeted Call (2018)

- Aboriginal and Torres Strait Islander LGBTQA+ team leadership

This project has 3 phases:

1 **Interviews and yarning groups**
Yarning with Aboriginal and Torres Strait Islander LGBTQA+ young people about their needs and experiences

2 **National survey**
An online national survey of Aboriginal and Torres Strait Islander LGBTQA+ young people's mental health and social emotional wellbeing

3 **Co-design**
Developing interventions with Aboriginal and Torres Strait Islander LGBTQA+ young people and services

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Project Design

Invitation from community

Study Design

Secure Funding

Consultation

Project Governance

Study Design

Consultation

Consultation

Study (re) design

Data Collection

Consultation

Consultation

Data Analysis

Knowledge Translation

Study Design

24 months
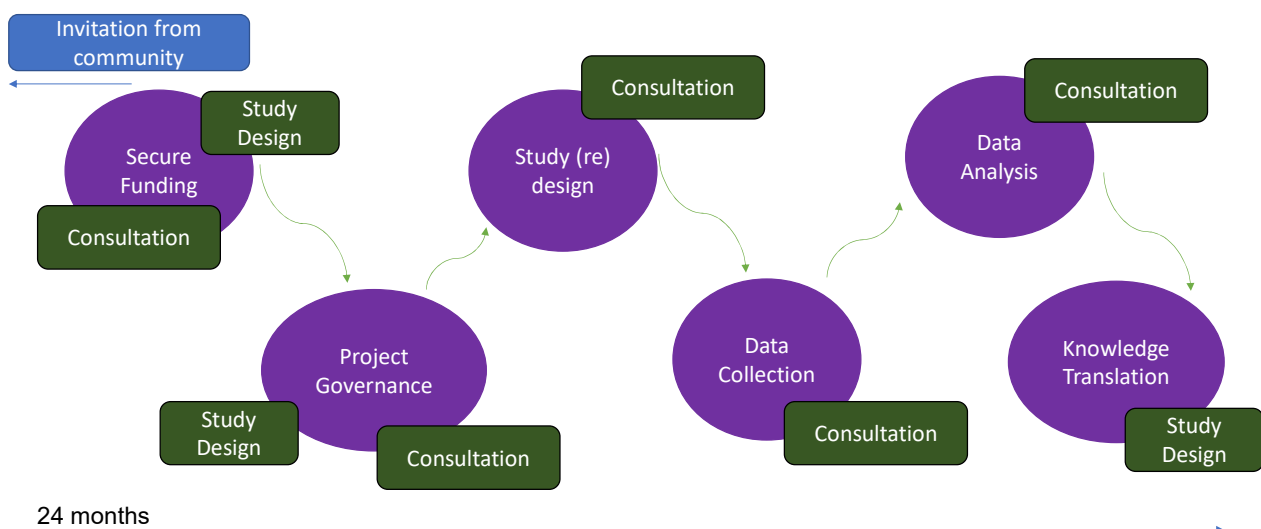
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Project Design – Youth Advisory Group

- 11 Aboriginal LGBQA+ young people (14-25 years) from across Australia

- Recruited through EOI process

- Reimbursed for time and expertise

- MS Team meetings

Secure Funding

Study Design

Consultation

Project Governance

Study Design

Consultation
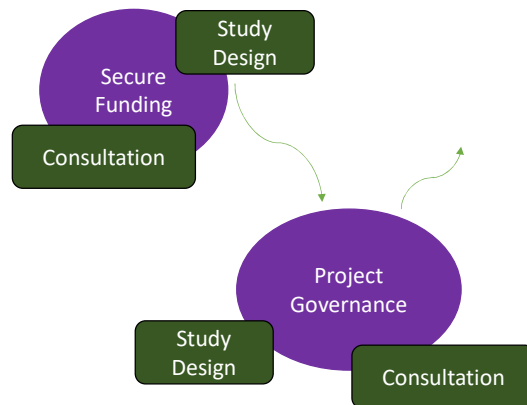
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Project Design – Youth Advisory Group

- Project research questions take to Youth Advisory Group for possible re-writing
  - Inclusion of focus on strengths, not just risks, in research questions
- Yarning method of data collection
- Removal of focus on intersex youth and addition of asexuality spectrum
- Project naming and artwork

Co-authorship reflecting genuine input:

Uink et al. (2020) The time for inclusive care for Aboriginal and Torres Strait Islander LGBTQ+ young people is now *Medical Journal of Australia*

Uink, B. et al. (forthcoming). Factors that promote social emotional wellbeing among Aboriginal and Torres Strait Islander LGBTQA+ youth. *Child Development*

Liddelow-Hunt et al. (2023). Conceptualising Wellbeing for Australian Aboriginal LGBTQA+ Young People. *Youth.*

22

Project Design – Governance Committee

- Project leadership and governance from a Governance Committee

- Went back to check on importance and framing of research questions
  - Who speaks for who?
  - How are we working with interstate projects?
  - Affirmation of yarning methodology
  - Project naming and artwork

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Project Design – Partnerships

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Phase 1

- Spoke with 14 Aboriginal LGBTQA+ young people

- Mainly women aged 18-25

- Mainly gay/lesbian or bisexual/pansexual

Gender
- Non-binary 1
- Cis man 3
- Cis woman 10

Sexuality
- Asexual 1
- Pansexual 4
- Gay/Lesbian 6
- Bisexual 4
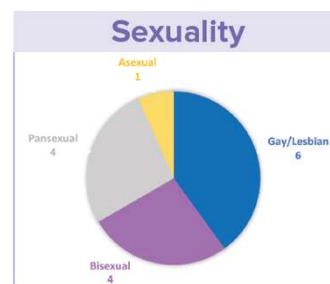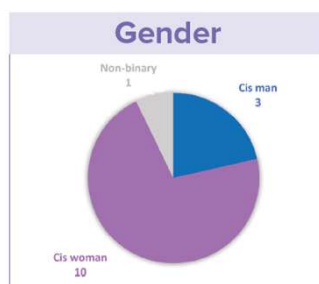
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Translation

Walkern Katatdjin Phase 1 Community Forum
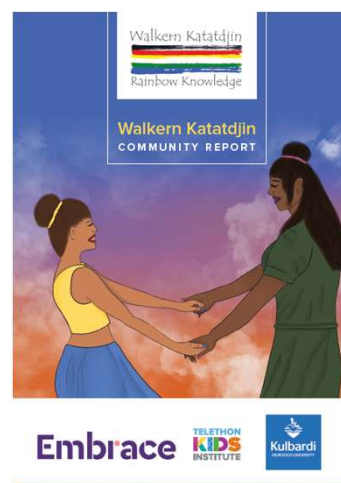
Community Report

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Phase 2

Phase 2: National online survey for people who are:

Aboriginal and Torres Strait Islander
LGBTQA+
Aged 14-25 years

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Ethics approvals

- Western Australian Aboriginal Health Ethics Committee (WAAHEC)

- Department of Health and Menzies School of Health Research Top End HREC (TEHREC)

- Central Australian Health Research Ethics Committee (CAHREC)

- Aboriginal Health Research Ethics Committee (AHREC)

- Aboriginal Health and Medical Research Council NSW (AH&MRC)

- Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS)
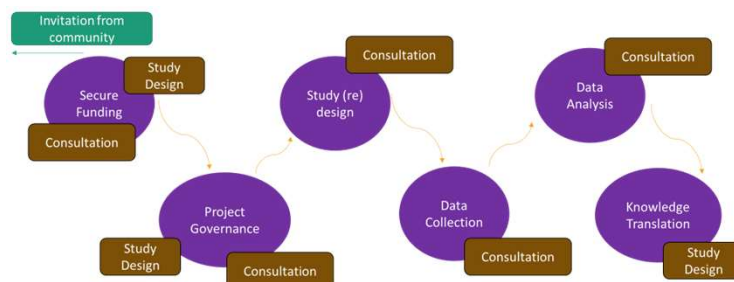
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Adjusting Partnerships and Governance Committee for national focus

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Survey development

- Re-read transcripts from Phase 1 to inform definitions of SEWB and mental health
    - One dominant, recurring concept → CONNECTION
- Led to selection of model of Social and Emotional Wellbeing (Gee et al., 2014)
- HOWEVER this model of social and emotional wellbeing was not developed with LGBTQA+ folk in mind, leading to inclusion of additional measures:
    - Visibility in community and media
    - Parent/caregiver, extended family and Elder acceptance
    - Pride in identity and identity centrality
    - Intersectional microaggressions

Uink, B. et al. (forthcoming). 'Factors that promote social emotional wellbeing among Aboriginal and Torres Strait Islander LGBTQA+ youth'.

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Knowledge Dissemination

- Community Research Forum
- Noongar Elders foru
- Community Report
- SUPPORT LGBTQA+ MOB ONLINE

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Knowledge Translation

- Knowledge translation
  - *Training health providers to work with Aboriginal and Torres Strait Islander LGBTQA+ young people* project
  - *Pride Yarns with Mob* project

- Resource development

- Policy and practice advise e.g., Department of Communities "Common Ground" Short Stay Aboriginal Accommodation project.

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Ensuring Indigenous Data Sovereignty

"Indigenous Data Sovereignty' refers to the right 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."

Steps taken:

- Define the 'data'
- Define the community
- Ensure appropriate data governance
- Develop data management plan
- Provide transparency
- Ensure appropriate review mechanisms

https://www.maiamnayriwingara.org/key-principles

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IDS for Walkern Katatdjin

What is Indigenous Data for Walkern Katatjdin?

Interviews and Yarning groups

All interviews and yarning group transcripts

National Survey

All responses to survey questions

➔Demographics

➔Social and emotional wellbeing

➔Experiences of discrimination

➔Psychological distress and suicidality

➔ Experiences in health services

Who owns the data we are going to collect?

Who is the Aboriginal and Torres Strait Islander LGBTQA+ youth community? Who speaks for who?

➔Decision for data to be governed by interested representatives from Aboriginal and Torres Strait Islander LGBTQA+ communities.

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Maiam nayri Wingara Principles

Principle	Step taken
1. Indigenous people should exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.	Establishment of a data governance mechanism
2. Data that is contextual and disaggregated (available and accessible at individual, community and First Nations levels).	Answering questions about Aboriginal & Torres Strait Islander LGBTQA+ young peoples' SEWB and mental health
3. Data that is relevant and empowers sustainable self-determination and effective self-governance.	Research questions that respond to community calls for data
	cont…

Maiam nayri Wingara Principles

Principle	Step taken
4. Data structures that are accountable to Indigenous peoples and First Nations.	Decisions about who can access the de-identified data made in conjunction with the Youth Advisory Group and Governance Committee
5. Data that is protective and respects our individual and collective interests.	Working through tension – LGBTQA+ voices are often left out of Aboriginal community conversations

Overcoming Institutional Barriers to IDS

Funder & university/institute considerations – standard grant agreement will state the IP sits with the host institution

- Contracts/legal process automatically excluded notions of IDS
- University legal teams not yet equipped for IDS discussions

Workarounds:

- Discussion with contracts team to include clause to respects IDS principles
- Memorandum of Understandings (MOU) between community organisation and host institute
- Strong data governance mechanisms
- Community organisations becoming host institutions in research
- Community-based infrastructure for storing and governing data?

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Overcoming Institutional Barriers to IDS

Grant/project funding is time limited
- In WK, YAG members and IGG members are paid…who will be responsible for data governance once the project funding expires?

Post-funding data governance:
- We will invite YAG members to volunteer to continue their role in data governance.
  - Should no YAG member volunteer, we will seek at-least two volunteers from the Indigenous LGBTQA+ youth community to uptake data governance.

- Data governance will additionally be shared with the Kulbardi Aboriginal Centre, Murdoch University.

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Key message

Research with Aboriginal communities should empower communities and provide the data that Aboriginal people need.

Nothing about us without us.

Acknowledgements

Upcoming Research Skills Sessions

8 Sep   Knowledge Translation
A/Prof Fenella Gill, CAHS/Curtin University

19 Sep   Advanced REDCap – Creating Surveys
Dr Jane Mugure Githae, REP Research Fellow

Register → **researcheducationprogram.eventbrite.com.au**

We love feedback
A survey is included in the back of your handout, or complete online
https://tinyurl.com/surveyAboriginalCommunities

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Government of **Western Australia**
Child and Adolescent Health Service

Perth Children's Hospital

TELETHON KIDS INSTITUTE

2023

Child Health Research Symposium

Celebrating Innovation, Collaboration and Translation

8 – 10 November 2023 Perth Children's Hospital

Scan me

Neonatology | Community Health | Mental Health | Perth Children's Hospital

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Child and Adolescent Health Service **Department of Research**
Department of Health, Government of Western Australia

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Involving Aboriginal Communities in Research

RESOURCE NOTES

Table of Contents

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

The Telethon Kid's Institute's [updated guidelines](#) are attached in full at the end of this document (online version only).

1. Ethics and human rights guidelines relevant to conducting research with aboriginal communities

The following documents are important and useful guides:

National Health and Medical Research Council Aboriginal Excellence Framework
https://www.nhmrc.gov.au/health-advice/aboriginal-and-torres-strait-islander-health

NHMRC [Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities | NHMRC](#)

NHMRC Keeping Research on Track 2006: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics
[Keeping research on track II | NHMRC](#)

AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research 2020
[Ethical research | AIATSIS](#)

United Nations Declaration on the Rights of Indigenous Peoples, 2008
http://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf

National Statement on Ethical Conduct in Human Research (2007) – updated 2018
https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018

Australian Code for the Responsible Conduct of Research (2007) – living document
http://www.nhmrc.gov.au/publications/synopses/r39syn.htm
http://www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/r39.pdf

2. Aboriginal research methodologies and principles

For further reading around research principles and methodologies for working with Indigenous peoples, as applied in Australia and internationally, please see the following articles and/or books:

Bessarab, D & Ng'andu B 2010, 'Yarning about yarning as a legitimate method in Indigenous research', International Journal of Critical Indigenous Studies, vol. 3, no.1, pp. 37-50.

Dudgeon, P 2008, 'Empowering research with Indigenous communities', Ngoonjook: a Journal of Australian Indigenous Issues, vol. 32, pp. 8-26.

Dudgeon, P, Kelly, K & Walker, R 2010, 'Closing the gaps in and through Indigenous health research: Guidelines, processes and practices.' Australian Aboriginal Studies, no. 2, pp. 81-91.

Jamieson, LM, Paradies, YC, Eades S et al 2012, 'Ten principles relevant to health research among Indigenous Australian populations', The Medical Journal of Australia, vol. 197, pp. 16-18.

Tuhiwai-Smith, L 2003, Decolonizing methodologies: Research and Indigenous People. University of Otago Press, Dunedin, NZ.

Wright M 2011, 'Research as intervention: Engaging silenced voices', Action Learning Action Research Journal, vol.17, no.2, pp. 21-41.

3. Working together with Aboriginal Communities

For more information about community capacity building strategies and working with Indigenous peoples please see the following:

Chino, M & DeBruyn, L 2006, 'Building true capacity: Indigenous models for Indigenous communities', *American Journal of Public Health,* vol. 96, no. 4, pp. 596-599.

Dudgeon, P, Milroy, H & Walker, R (eds) 2014, *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice*, 2nd edn. Commonwealth Attorney-General's Department, Canberra ACT.

Hunt J, 2013, Engaging with Indigenous Australia—exploring the conditions for effective relationships with Aboriginal and Torres Strait Islander communities. Australian Institute of Health and Welfare & Melbourne: Australian Institute of Family Studies: Produced for the Closing the Gap Clearinghouse, Canberra ACT.

4. Co-production and participatory action research

For a general overview of co-production please refer to:

Boyle, D, Coote, A, Sherwood, C & Slay, J 2010, 'Right Here, Right Now: Taking co-production into the mainstream. Nesta, London, UK. This discussion paper is available online at:
http://www.nesta.org.uk/publications/co-production-right-here-right-now

Minkler M & Wallerstein N (eds) 2010, Community-Based Participatory Research for Health: From Process to Outcomes. 2nd edn. Jossey-Bass, San Francisco.

5. Useful websites and documents

5.1. The Australian Indigenous HealthInfoNet

http://www.healthinfonet.ecu.edu.au/
The Australian Indigenous HealthInfoNet is an innovative internet resource that aims to inform practice and policy in Aboriginal health by making research and other knowledge readily accessible.

See also: Summaries of Australian Indigenous health status
http://www.healthinfonet.ecu.edu.au/health-facts/summary

5.2. The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS)

http://aiatsis.gov.au
AIATSIS is a world-renowned research, collections and publishing organisation which promotes knowledge and understanding of Aboriginal and Torres Strait Island cultures, traditions, languages and stories, past and present.

5.3. Lowitja Institute

http://www.lowitja.org.au/
The Lowitja Institute is Australia's national institute for Aboriginal and Torres Strait Islander health research.

5.4. Aboriginal Health Council of WA (AHCWA)

http://www.ahcwa.org.au/
The Aboriginal Health Council of WA (AHCWA) is the peak body for the 21 Aboriginal Community Controlled Health Services (ACCHSs) in Western Australia. ACHWA acts as a forum to lead the development of Aboriginal Health policy, to influence and monitor performance across the health sector, to advocate for and support community development and capacity building in Aboriginal Communities, and to advocate for the rights and entitlements of all Aboriginal people throughout Western Australia, at a local, regional, State and National level.

5.5. Western Australian Aboriginal Health Ethics Committee (WAAHEC)

The Western Australian Aboriginal Health Ethics Committee (WAAHEC) operates through ACHWA and is recognised and registered with the National Health and Medical Research Council (NHMRC).

For information about meeting dates, the research application process and required forms see: http://www.ahcwa.org.au/#!ethics/c6gq

The WAAHEC Policy and Procedures Manual is a very helpful document:

https://docs.wixstatic.com/ugd/539530_ba3e00a314b14c1ca3ade61e5b934594.pdf

5.6. Australian Human Rights Commission

Questions and Answers about Aboriginal & Torres Strait Islander Peoples. Australian Human Rights Commission.

https://www.humanrights.gov.au/publications/questions-and-answers-about-aboriginal-torres-strait-islander-peoples

5.7. Australian Indigenous Doctors Association

https://aida.org.au/

5.8. Australian Allied Health Australia

https://iaha.com.au/

5.9. Congress of Aboriginal Torres Strait Islander Nurses and Midwives

https://catsinam.org.au/

5.10. National Aboriginal Community Controlled Health Organisation

https://www.naccho.org.au/

5.11. National Association of Aboriginal and Torres Strait Islander Health Workers and Health Practitioners

https://www.naatsihwp.org.au/

6. Aboriginal Health Impact Statement and Declaration for WA Health

https://ww2.health.wa.gov.au/~/media/Corp/Policy-Frameworks/Clinical-Services-Planning-and-Programs/Aboriginal-Health-Impact-Statement-and-Declaration-Policy/MP0160-21-Mandatory-Policy-AHISD.pdf

Applicable to: This Policy is applicable to all WA Health system entities as defined by this policy.

Description: The Aboriginal Health Impact Statement and Declaration Policy outlines requirements to declare and demonstrate that the interests of, potential impacts on, and opportunities for, Aboriginal people are considered and appropriately embedded within policy development processes.

Consulting with Aboriginal stakeholders will inform and increase Aboriginal cultural understanding in the provision of health services.

The **WA Aboriginal Health and Wellbeing Framework 2015-2030 (Framework)** provides the guiding principles that underpin the requirement for this Policy. The Framework recognises that a culturally respectful and non-discriminatory health system is a key enabler to improve health outcomes for Aboriginal people. Strategic Direction 4.3: A culturally respectful and non-discriminatory health system articulates the need to embed structures, policies, and processes across health to ensure a culturally respectful and non-discriminatory health system can be achieved.

This Policy supports a whole-of-organisation approach and an ongoing commitment to grow and sustain a culturally responsive WA health system.

This Policy is a mandatory requirement under the Clinical Services Planning and Programs Policy Framework pursuant to section 26(2)(d) and 34(2)(c) of the *Health Services Act 2016.*

This Policy is also a mandatory requirement for the Department of Health pursuant to section 29 of the *Public Sector Management Act 1994.*

Date of effect: 11 May 2021

6.1. WA Aboriginal Health and Wellbeing Framework 2015-2030

https://ww2.health.wa.gov.au/~/media/Files/Corporate/general-documents/Aboriginal-health/PDF/12853_WA_Aboriginal_Health_and_Wellbeing_Framework.pdf

The WA Aboriginal Health and Wellbeing Framework 2015–2030 (the Framework) (PDF 10MB) identifies key guiding principles, strategic directions and priority areas for the next 15 years, to improve the health and wellbeing of Aboriginal people in Western Australia.

This Framework has a long-term agenda and encourages an approach for WA Health, the health sector and other key stakeholders to adopt and guide future activities for Aboriginal people living in WA.

The Framework has been developed for Aboriginal people by Aboriginal people and was informed by an extensive consultation program. It has a strong focus on prevention and acknowledges culture as a key determinant of health.

6.2. Supporting information

View the User-Guide-for-Aboriginal-Health-Impact-Statement-and-Declaration https://ww2.health.wa.gov.au/~/media/Corp/Policy-Frameworks/Clinical-Services-Planning-and-Programs/Aboriginal-Health-Impact-Statement-and-Declaration-Policy/Supporting/User-Guide-for-Aboriginal-Health-Impact-Statement-and-Declaration.pdf

View the National Safety and Quality Health Service Standards User Guide for Aboriginal and Torres Strait Islander health https://www.safetyandquality.gov.au/publications-and-resources/resource-library/nsqhs-standards-user-guide-aboriginal-and-torres-strait-islander-health

View the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 https://www1.health.gov.au/internet/main/publishing.nsf/content/B92E980680486C3BCA257BF0001BAF01/$File/health-plan.pdf

View the Cultural Respect Framework 2016-2026 for Aboriginal and Torres Strait Islander Health
http://www.coaghealthcouncil.gov.au/Portals/0/National%20Cultural%20Respect%20Framework%20for%20Aboriginal%20and%20Torres%20Strait%20Islander%20Health%202016_2026_2.pdf

View the United Nations Declaration on the Rights of Indigenous Peoples
DRIPS_en.pdf (un.org)

View the Monitoring and reporting plan for the WA Aboriginal Health and Wellbeing Framework 2015–2030
https://ww2.health.wa.gov.au/~/media/Files/Corporate/general-documents/Aboriginal-health/PDF/Aboriginal-health-framework-monitoring-reporting-plan.pdf

View the Implementation Guide for the WA Aboriginal Health and Wellbeing Framework 2015–2030
https://ww2.health.wa.gov.au/~/media/Files/Corporate/general-documents/Aboriginal-health/PDF/13283-implementation-guide-final.pdf

7. WA Health Aboriginal Cultural e-Learning – a healthier future

WA Health is committed to improving the health of Aboriginal people and providing staff with access to Aboriginal Cultural Learning is a priority in achieving this outcome.

The WA Aboriginal Health and Wellbeing Framework 2015-2030 (PDF 10MB) identifies 'a culturally respectful and non-discriminatory health system' as a WA Health strategic direction.

This can be achieved by providing Aboriginal cultural education and training opportunities which builds the health system's capacity, capability and responsiveness to service the health needs of Aboriginal people living in Western Australia. Attaining cultural competency is an ongoing process that requires continuous reflection and review for the health professional, health services and health system.

The Aboriginal Cultural eLearning (ACeL) - *Aboriginal Health and Wellbeing* is a _new_ (released April 1 2021) cultural learning course that builds on previous ACeL courses to enable people to develop their cultural competency and to improve cultural safety for Aboriginal patients.

The training covers key concepts such as:

- The cultural determinants of health.

- Aboriginal people experience and access of health services.

- Historical and contemporary factors that impact Aboriginal people's current health and wellbeing, including implicit bias and systemic racism.

- Personal and organisational practices that can be reshaped to better meet the needs of Aboriginal people and communities.

The Director General has mandated that all WA health staff complete the new ACeL training, even if they have completed previous ACeL courses (under the MP 0065/17 Aboriginal Cultural eLearning Policy - https://ww2.health.wa.gov.au/About-us/Policy-frameworks/Employment/Mandatory-requirements/Human-Resource-Management/WA-health-system-policies/Aboriginal-Cultural-eLearning-Policy). Employees who have completed the previous ACeL training will have a two-year period to complete the new course. Other employees and new starters will have six months to complete the ACeL.

The online course takes about 1.5 hours to complete and can be claimed towards continuing professional development (CPD) points. Staff can enter and leave the course as they need to, and start from where they finished off last time.

The Aboriginal Cultural eLearning will be available via the employees relevant DOH or HSP Learning Management Platform.

7.1. The journey of health and wellbeing

The Journey of Health and Wellbeing animated video helps to promote understanding of Aboriginal people's experience from colonisation to the present day.

The 10-minute animation shows how events of the past play out in the present and offers a framework of hope and equity.

Watch more of our videos at the WA Health YouTube channel (external site) http://www.youtube.com/user/wahealth/

8. Key Aboriginal Health Contacts

Aboriginal Health, a statewide office within WA Health, is responsible for facilitating a collaborative and coordinated approach within WA Health's public health system to improve health outcomes for all Aboriginal people living in Western Australia. Aboriginal Health is principally positioned to provide high level strategic leadership including advice for matters which directly and indirectly impact health outcomes.

For more information contact:

Aboriginal Health
Department of Health
Ground Floor, C Block
189 Royal Street
EAST PERTH WA 6004

Phone: 9222 2478
Email: Aboriginal.Health@health.wa.gov.au

9. National Peak Aboriginal research and ethics organisations

- o Western Australian Aboriginal Health Ethics Committee
  https://www.ahcwa.org.au/ethics

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

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

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

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

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

10. Aboriginal Status

Are you of Aboriginal or Torres Strait Islander? Why we need to ask you this question. CAHS brochure PMH May 2014 CAHS 0816

https://cahs-healthpoint.hdwa.health.wa.gov.au/directory/aboriginalhealth/Cultural%20Learning%20Documents/CAHS%20Patient%20Care%20and%20Cultural%20Learning%20Guidelines%202016.pdf [accessible by WA Health staff only]

11. Telethon Kids Institute Kulunga Aboriginal Unit

The Kulunga Aboriginal Unit is the primary professional services unit in Telethon Kids Institute that supports researchers conducting Aboriginal health research and links Aboriginal communities and organisations with key research that will work towards closing the gap in the health and wellbeing of Aboriginal children and families.

Kulunga is the core Aboriginal Unit of the Telethon Kids Institute and has four goals:

1. Provide support, advice and community navigation for all Telethon Kids researchers focused on the health and wellbeing of Aboriginal children and families to ensure the research responds to community needs and meets the standards for Aboriginal Health Research.

2. Provide cultural training and oversight of cultural governance within research projects.

3. Provide training and support for all Aboriginal people involved in conducting the Telethon Kids research effort, now and in the future, and enable their career trajectory.

4. Build awareness and understanding of Telethon Kids research in Aboriginal communities.

The key focus of the Unit is to facilitate research interest and opportunities that involve Aboriginal families and communities as well as building the capacity and development of Institute researchers working on Aboriginal projects.

Contact: Cheryl Bridge, Kulunga, Head (Perth) - Cheryl.Bridge@telethonkids.org.au

CAHS Research Education Program

Research Skills Seminar Series 2023

A free, open-access resource designed to upskill busy clinical staff and students and improve research quality and impact

Knowledge Translation

8th September 2023

12.30-1.30pm

Ensuring that research findings are translated into practice involves a systematic approach from the beginning when you are designing your research. Implementation science bridges the gap between developing and evaluating effective interventions and implementation and de-implementation in routine practice. This seminar covers key elements of implementation research; theoretical approaches, research designs, involvement of stakeholders, behaviour change interventions.

Perth Children's Hospital Auditorium

Level 5, 15 Hospital Ave Nedlands
Accessible via pink or yellow lifts
- OR -
Access online via Teams or Avaya
- OR -
Watch live
from a hosted video-conferencing site

- Bunbury Hospital
- Fiona Stanley Hospital
- Lions Eye Institute
- Royal Perth Hospital

Register via Eventbrite

View recorded seminars online

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Curtin University

Meet the presenter

A/Prof Fenella Gill
Nursing Research, PCH, CAHS
School of Nursing, Curtin University

Fenella leads research focused on paediatric inpatient and family experiences, safety and outcomes. Fenella's PhD work resulted in national practice standards for critical care nurse education incorporating the views of health consumers. Fenella was an NHMRC Translating Research into Practice Fellow for post-doctoral research on partnering with parents in the care of their deteriorating child in hospital.

Fenella holds an inaugural West Australian HealthTranslation Network (WAHTN) and Curtin University 2019 Early Career Fellowship in Research Translation and in 2016 Fenella was honoured as a life member of the Australian College of Critical Care Nurses (ACCCN).

Scan here to register

✉ researcheducationprogram@health.wa.gov.au   ☎ (08) 6456 0514

🌐 cahs.health.wa.gov.au/Research/For-researchers/Research-Education-Program

CAHS Research Education Program
Research Skills Seminar Series 2023

A free, open-access resource designed to upskill busy clinical staff and students and improve research quality and impact

Research Governance

13th October 2023

12.30 - 1.30pm

All new research project applications must cover requirements for both ethics and governance. This seminar focuses on the general principles and responsibilities related to research governance, and provide practical tips for preparation of governance applications.

It also covers recent changes to state and national governance frameworks and implications for researchers.

Perth Children's Hospital Auditorium

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Meet the presenter

Dr Natalie Giles
Manager, Ethics and Compliance, CAHS

Natalie has a background as researcher prior to moving into research ethics. She initially worked in the field of immunology and later completed a PhD in biomedical science from Murdoch University.

She worked as a post-doctoral researcher for the Fiona Wood Foundation, known as the McComb Foundation at the time. Natalie then took on a research ethics role at the University of Notre Dame Australia and later at South Metropolitan Health Service prior to joining CAHS.

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CAHS Research Education Program

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A free, open-access resource designed to upskill busy clinical staff and students and improve research quality and impact.

2023 Seminar Schedule

Interactive in pdf format
Last updated 31/8/23

	DATE	TOPIC	PRESENTER	ENROL	WATCH
1	3 Mar	**Research Fundamentals**	Dr Kenneth Lee, UWA	-	2023
2	17 Mar	**Introductory Biostatistics**	Michael Dymock, TKI	-	2023
3	28 Apr	**Scientific Writing**	A/Prof Tony Kemp, UWA	-	2023
4	5 May	**REDCap for Data Capture and Management**	Dr Jane Mugure Githae, CAHS	-	2023
5	12 May	**Using Social Media in Research**	Dr Kenneth Lee, UWA	-	2023
6	19 May	**Getting the Most out of Research Supervision**	A/Prof Sunalene Devadason, UWA/CAHS	-	2022
7	26 May	**Research Impact**	Dr Tamika Heiden, Vic	-	2023
8	2 Jun	**Survey Design & Techniques**	Dr Jane Mugure Githae, CAHS	-	2023
9	9 Jun	**Conducting Systematic Reviews**	Prof Sonya Girdler, Curtin Uni	-	2023
10	16 Jun	**Consumer & Community Involvement in Research**	Belinda Frank, TKI	-	2023
11	23 Jun	**Project Management**	Melanie Wright, SMHS	-	2023
12	30 Jun	**Sample Size Calculations**	Michael Dymock, TKI	-	2023
13	21 Jul	**Introduction to Good Clinical Practice**	Alexandra Robertson, CAHS	-	2023
14	28 Jul	**Data Collection and Management**	Dr Jane Mugure Githae, CAHS	-	2023
15	4 Aug	**Rapid Critical Appraisal of Scientific Literature**	Dr Natalie Strobel, ECU	-	2023
16	18 Aug	**Media and Communications in Research**	Keryn McKinnon, TKI	-	2023
17	25 Aug	**Oral Presentation of Research Results**	Dr Jane Mugure Githae, CAHS	-	2023
18	1 Sep	**Involving Aboriginal Communities in Research**	Cheryl Bridge, Mara West, Shakara Liddelow - Hunt – TKI + A/Prof Bep Uink, Murdoch Uni	-	2022
19	8 Sep	**Knowledge Translation**	A/Prof Fenella Gill, Curtin Uni / CAHS	REGISTER	2021
20	13 Oct	**Research Governance**	Dr Natalie Giles, CAHS	REGISTER	2022
21	20 Oct	**Grant Applications and Finding Funding**	Dr Tegan McNab, TKI	REGISTER	2022
22	27 Oct	**Statistical Tips for Interpreting Scientific Claims**	Michael Dymock, TKI	REGISTER	2022
23	17 Nov	**Ethics Processes for Clinical Research in WA**	Dr Natalie Giles, CAHS	REGISTER	2020
24	24 Nov	**Qualitative Research Methods**	Dr Shirley McGough, Curtin Uni	REGISTER	2022
25	1 Dec	**Innovation and Commercialisation**	Dr Helga Mikkelsen, Brandon BioCatalyst + Ashley Schoof, TKI	REGISTER	2022

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Seminars are held from 12:30-1:30pm at Perth Children's Hospital Auditorium and are broadcast live online through Teams and Avaya. Seminars are recorded and uploaded to our website within a week of presentation. Topics are subject to change with appropriate email notice provided. Handouts are revised and updated regularly. A light lunch is provided for attendees at our PCH auditorium. Attendance certificates are available on request.

2023

Child Health Research Symposium

Celebrating Innovation, Collaboration and Translation

cahs.health.wa.gov.au/Child-Health-Research-Symposium

📅 **8 - 10 November 2023**

📍 Perth Children's Hospital Auditorium and Telethon Kids Institute Manda

PLUS

breakfast sessions and poster evening event

Incorporating the CAHS Nursing and CAMHS Symposiums

Neonatology | Community Health | Mental Health | Perth Children's Hospital

Guidelines for the
Standards for the Conduct of Aboriginal Health Research

CONTENTS

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 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.

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 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.

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:

IMPACT	PARTNERSHIPS	PEOPLE	SUSTAINABILITY
Making a measurable difference	We work better when we work with others	Capacity to take on the toughest challenges	Meeting needs now and for the future
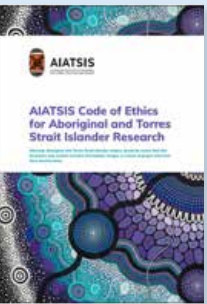
The best practice advice from the NHMRC are the 'Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders 2018' and 'Keeping research on track II' (companion document to *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities)*. The AIATSIS best practice advice is the 'Code of Ethics for Aboriginal and Torres Strait Islander Research'.

RESEARCH GOVERNANCE FRAMEWORK
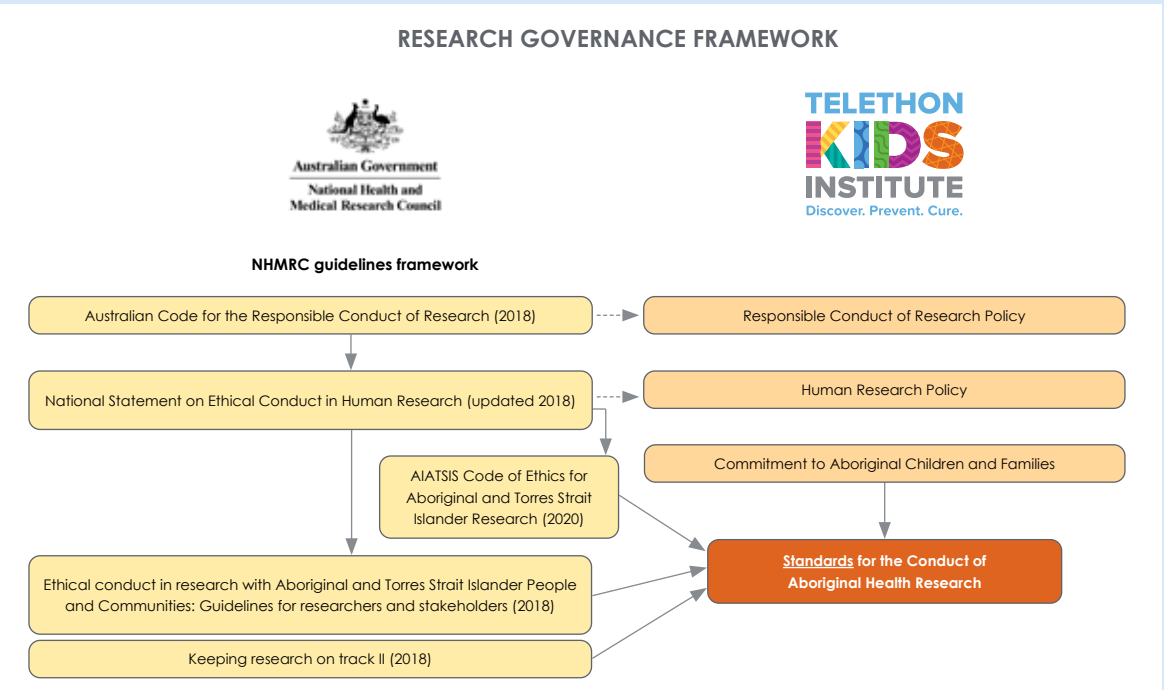
Figure 1 | *NHMRC guidelines, AIATSIS and Telethon Kids Institute frameworks*

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*

ABORIGINAL GOVERNANCE AND RELATIONSHIPS
- Getting a community perspective and building relationships
- Ensuring excellence through cultural security
- Aboriginal leadership & governance

FORMULATE THE RESEARCH QUESTION
- Planning for success: Start with the end in mind
- Prioritise Aboriginal peoples' and communities' perspectives
- Confirm Community buy-in and strengthen relationships
- Choose the most appropriate methodology(ies) for research proposal

PROPOSAL AND FUNDING
- Confirm data ownership and intellectual property (for research and community)
- Develop proposal
- Update community and/or external stakeholders about funding opportunities

PROJECT GOVERNANCE AND ETHICS
- Develop research and governance protocol
- Develop ethics and governance applications (confirm community governance and participation)
- Engage with relevant regional Aboriginal health & planning forums (eg KAHPF & PAHF)

DATA COLLECTION AND SAFETY MONITORING
- Hold "kick-off" meeting and include community and relevant stakeholders
- Employ local and build capability and capacity
- Undertake relevant training eg. Good Clinical Practice and local Cultural Awareness

ANALYSIS AND REPORTING
- Analyse results together
- Report back to community and stakeholders (stay connected)
- Proper acknowledgement and recognition

TRANSLATION
- Share findings in a way that is relevant to communities
- Explore other translation opportunities eg co-authorship, co-conference presentations, health promotions

EVALUATION
- What is the benefit for communities on the ground
- Has the research met desired results
- Learning from research and planning next steps

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.

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.

Submission of ethics proposal:

All relevant Aboriginal community perspectives and considerations for a successful WAAHEC ethics approval <u>will have already been met</u> 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.

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.

---

1 — Building Relationships

IDEATION

Contact Kulunga (KAU):

KAU 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 <u>Relational</u>** (genuinely considers communities' needs, wholistic for whole of TKI, is ongoing), **not <u>Transactional</u>** (more about benefit to TKI/Research team, for one project in isolation of others, is limited).

2 — Formulate Research Question

Grants ITA (& Contract or Philanthropic funding):

Meet with KAU, Community Engagement 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 often missed or given insufficient consideration (e.g. community reference group, communication materials, events, employment, capacity building including workforce and/or training, funding, honorariums).

3 — Proposal and Funding

PLANNING THE RESEARCH

4 — Governance and Ethics Approval

In the field:

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.

5 — Data collection and Safety Monitoring

HOW WE DO OUR RESEARCH

6 — Analysis and Reporting

WHAT DID WE FIND OUT

7 — Translation

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.

8 — Evaluation

HOW DID WE DO

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

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)

- ❯ 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

- ❯ 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

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

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

KULUNGA Team:

✉ 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

- 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

- Lowitja Intstitue 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

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)

THANKS

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Involving Aboriginal Communities in Research

Thank you for your interest in this seminar
Please complete this 1-minute evaluation.
Your feedback will help guide future presentations and educational activities.

How did you attend the seminar?

○ Live seminar at Perth Children's Hospital
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○ Online via Avaya or Teams
○ Viewed online recording

Please rate your agreement with the following statements:

	N/A	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree
The aims and objectives were clear	○	○	○	○	○	○
The session was well structured	○	○	○	○	○	○
Presentation style retained my interest	○	○	○	○	○	○
The speaker communicated clearly	○	○	○	○	○	○
The material extended my knowledge	○	○	○	○	○	○
The additional resources were helpful	○	○	○	○	○	○

What were the best aspects of the seminar?

What changes or improvements would you suggest?
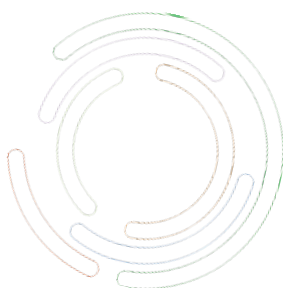
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