

Aboriginal and Torres Strait Islander health research

PURPOSE

This guideline provides an overview of considerations of Aboriginal and/or Torres Strait Islander (respectfully hereafter referred to as First Nations) health research and outlines best practice recommendations for Metro South Health (MSH) researchers to consider when planning research in partnership with Aboriginal and/or Torres Strait Islander peoples.

OUTCOME

This guideline may enhance researcher knowledge and skills surrounding:

1. The principles of conducting and co-designing health research with Aboriginal and/or Torres Strait Islander peoples.
2. Considerations when building relationships and formulating research proposals focussed on Aboriginal and/or Torres Strait Islander health and wellbeing.
3. How MSH maintains a strengths-focussed approach that supports Aboriginal and Torres Strait Islander health research activity through strategies, policies, and resources.

SCOPE

This guideline applies to all MSH employees and collaborators who conduct human research within or in association with MSH, or through access to MSH participants, health records or data.

GUIDELINE

Co-designing research with First Nations people in Australia requires a respectful, culturally responsive, or culturally secure, and ethical approach. First Nations Communities in Australia are strong, and continue to evolve and thrive, despite ongoing intergenerational trauma, dispossession, and systemic discrimination and racism resulting from the impacts of colonisation. Researchers require a unique set of skills, knowledge, approaches, and reflexivity to appropriately conduct research in this space. This guideline will help researchers navigate the complexities and ethics involved in such research.

Refer to National Health and Medical Research Council (NHMRC) resources when considering research in partnership with Aboriginal and Torres Strait Islander peoples:

- [National First Nations Research Network NHMRC](#) – a national network for Aboriginal and Torres Strait Islander health researchers brings together unique skills across culture, knowledge and health research to address the health priorities of Aboriginal and Torres Strait Islander Communities.
- [Ethical conduct in research with Aboriginal and Torres Strait Islander peoples and communities: Guidelines for researchers and stakeholders 2018](#)
- [Keeping research on track II 2018.](#)

The above documents should be read alongside the [AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research 2020](#), developed by the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS). All project conceptualisation, design and conduct should follow the principles set out in the documents above.

The [Guidelines Framework](#) shows how the relevant research guidelines in Australia are linked and provides a framework for how researchers and participants can work together on research in partnership with First Nations people and Communities. Adherence to these guidelines will be a requirement of the NHMRC funding agreements.

1. WHAT IS DIFFERENT ABOUT ABORIGINAL AND/OR TORRES STRAIT ISLANDER HEALTH RESEARCH?

Aboriginal and Torres Strait Islander health research, also referred to as First Nations health research, is a specialised field of study that focuses on research related to and conducted in collaboration with the First Nations peoples of Australia with the aim to optimise health and wellbeing. First Nations health research in Australia shares many characteristics with Indigenous or First Nations health research globally, but it is focussed specifically on the historical, cultural, and social contexts of Australia's First Nations Communities.

Conducting research with First Nations peoples in Australia requires an understanding of First Nations' concept of health and wellbeing, the unique cultural values across the diversity of Communities, languages, and cultural ways of knowing, being and doing.

MSH researchers should ensure that the health research undertaken collaborates in a meaningful, ethical, responsible and beneficial way with First Nations people, these ways are defined by Communities themselves. The values of spirit and integrity, cultural continuity, equity, reciprocity, respect and responsibility should be upheld across all phases of research (NHMRC, 2018). Principles of Aboriginal and Torres Strait Islander self-determination, leadership, research impact and value, and sustainability and accountability should also guide research that partners with Aboriginal and Torres Strait Islander people (AIATSIS, 2020).

2. WHAT RESEARCHERS SHOULD CONSIDER

When considering undertaking research in partnership with/alongside First Nations peoples, it is important to:

- Reflect on personal racial consciousness and cultural awareness. Researchers should position themselves in the research before they begin (Wilson, 2014).
- Recognise and respect that not all First Nations people are the same, just as not all White people are the same. The land now called Australia is home to over 250 different First Nations Countries, each with their own cultural traditions, languages, customs, and connection to the land, skies and waterways. Prior to conducting research, researchers should take the time to educate themselves about the Community group they will be working with, their Country and local protocols.
- Engage with the Community and establish a respectful and ongoing relationship with the Community they wish to collaborate with by engaging Community members in the research process. This relationship-building process should be authentic, transparent, and patient. To do this properly takes time. It is vital not to rush this process.

Research partnering with First Nations people should be led and governed by First Nations people. If researchers do not identify as a First Nations person, then it is imperative to set-up an Advisory Group or Governance Committee that will guide, advise, and ensure the research is conducted appropriately and safely.

Researchers should also consider cultural sensitivities when conducting research. Some topics may be taboo or sacred, and it is essential to respect these boundaries. It's also important to ensure Aboriginal and Torres Strait Islander people's knowledge and practices are valued and integrated into research where appropriate (e.g., Men's Business and Women's Business, Elders are offered to talk first).

When preparing their research, it is important for researchers to:

- seek support and approval for research from First Nations Communities. It is required as part of the Metro South Human Research Ethics and Governance process. Ensure this has been completed prior to obtaining ethical clearance from a Human Research Ethics Committee (HREC):
 - [Metro South Health Aboriginal and Torres Strait Islander Health](#)
 - [The Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care](#)
 - [Inala Community Jury for Health Research \(Inala Community Jury\)](#)
- partner with Community to co-design the research, including research need, design, methods used, analysis and dissemination. Community may also want information about how the project will benefit Community, and how project resources (i.e., grant funding) will be used to improve First Nations health research workforce in their Community.
- obtain ethical clearance before beginning any research from a Human Research Ethics Committee (HREC). When developing their proposal, researchers should refer to the NHMRS and AIATSIS guidelines. Researchers should use a tool like the Aboriginal and Torres Strait Islander Quality Assurance Tool (Harfield et al., 2020) to ensure their proposal has been planned appropriately.
- ensure that researchers and their research team undergo cultural competency or awareness training. This training should include cultural sensitivity, an understanding of colonial history and policies and practices of the past causing historical trauma, and knowledge about the unique customs and protocols of the specific Community they are working with. Internal MSH training programs are available via MSHLearn. It is highly recommended the research team complete additional, external courses:
 - AIATSIS – [CORE: Ethics for Aboriginal and Torres Strait Islander Research](#)
 - Lowitja – [Introduction to Aboriginal and Torres Strait Islander Research](#)
- learn and adhere to the cultural protocols of the Community, which may include paying respects to Elders, understanding kinship systems, and acknowledging traditional custodians of the land. Ask about what local cultural protocols researchers should be aware of prior to engaging with Community.
- obtain informed consent from all research participants. Ensure the consent process is culturally responsive/culturally secure. As with all research projects, provide information in a language and format that potential participants can understand. Where possible, have a First Nations researcher or health worker/liaison officer discuss research consent with the potential participant. Use plain language and visual aids if necessary (drawing pad & pen to focus conversation). [Aboriginal and Torres Strait Islander Hospital Liaison Services](#) and Health Workers are available at Metro South facilities.

- consider remuneration as per MSH procedure PR2021-285 Remuneration and reimbursement of consumer partners for those First Nations People who may be on any health research committee and those First Nations People who participate in health research as per the MSH policy PL2019-64 Consumer partnering.
- discuss the initial research findings with the Community. Community may have suggestions about how the data relating to their Community is analysed.
- seek Community approval regarding the dissemination of research findings (i.e., through publication or presentation at conferences).
- not conduct research to benefit the research team.
- ensure Community are aware of how the research findings will be translated into benefits for themselves and their Community.
- properly acknowledge and give credit to Community members who contribute to the research. Discuss authorship and co-authorship with Community members where appropriate.
- be respectful by acknowledging time and knowledge sharing with gift vouchers for both research participants and Community members who have contributed to the research. Ensure this is included in the research budget.
- maintain a long-term relationship with the Community, showing gratitude and respect for their participation.
- continuously seek feedback and learn from your experiences to improve future research collaborations.

3. METRO SOUTH HEALTH POLICIES AND PLANS

In the delivery of services to Aboriginal and Torres Strait Islander peoples, MSH staff are guided by strategies, service plans and policies. Refer to the [Aboriginal and Torres Strait Islander Health](#) intranet page for more information and links to resources.

4. FUNDING FOR ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH, MEDICAL RESEARCH AND RESEARCHERS

The [NHMRC](#) funds First Nations health research across all its funding schemes. In addition, it has established specific funding schemes to support research in priority areas and to build capacity in Indigenous health:

- [Indigenous Research Excellence Criteria](#)

The [Metro South Health Research Support Scheme \(RSS\)](#), is an internal, annual research grants funding program, administered by the Metro South Research office. The MSH RSS aims to facilitate high quality research that will deliver improved health outcomes for all in our community. The MSH RSS includes categories aimed at supporting Aboriginal and Torres Strait Islander research:

- Aboriginal and Torres Strait Islander Novice Researcher Grant
- Indigenous Health Research Project Grant (IHR)

5. ETHICS AND SITE SPECIFIC ASSESSMENT AND ABORIGINAL AND TORRES STRAIT ISLANDER RESEARCH

Ethical approval is not required to engage with Aboriginal and Torres Strait Islander peoples however a HREC may require a Letter of Support from Community.

In MSH, the Metro South Human Research Ethics Committee (MSHREC) requires a Letter of Support from the Community where the research is being conducted. For projects being conducted at the Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Healthcare (Inala Indigenous Health Service), the Inala Community Jury who interrogate the need, design, methods, budget and expected outcomes, and advise the research team prior to HREC review.

The Inala Community Jury require that research findings are presented to the Jury before dissemination. More information can be provided by the Southern Queensland Centre of Excellence for Aboriginal and Torres Strait Islander Healthcare.

Consideration also needs to be given to whether Aboriginal and Torres Strait Islander researchers are listed as investigators on the Human Research Ethics Application (HREA). Whether researchers do this or not depends on the level of involvement that those engaged will have:

- If Aboriginal and Torres Strait Islander peoples are key members of the research team and partners throughout the life of the research project, it is appropriate to list them as co-investigators on the HREA.
 - **Note:** Partnering is vital - it is not appropriate to list an Aboriginal and Torres Strait Islander researcher in a tokenistic way as member of a research team or co-investigator on a grant as means to secure funding (i.e., where an Aboriginal and Torres Strait Islander person is consulted initially and then not consulted again during the research project).
- If interactions with Aboriginal and Torres Strait Islander peoples are likely to be once-off or occurring at sporadic times throughout the research (such as providing feedback on the research design or reviewing documents) there is no need for representatives to be listed as Aboriginal and Torres Strait Islander researchers on the HREA.
 - **Note:** Any Aboriginal and Torres Strait Islander peoples listed on the research team are unable to be participants in the research study itself as this generally constitutes a conflict of interest.
- MSH work instruction WI2023-299 Ethical and scientific review of research provides more information.

5.1 Authorship

When completing a HREA for their research, researchers may notice there is a section about peer review. This is where they should outline any Aboriginal and Torres Strait Islander engagement activities they have undertaken or plan to undertake for their research.

MSH work instruction WI2023-290 Research authorship, peer review and publication provides more information.

5.2 Site Specific Assessment (SSA)

Evidence of relevant community engagement with Aboriginal and Torres Strait Islander individuals, Communities and/or organisations in the conceptualisation, development and approval, data collection and

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management, analysis, report writing, and dissemination of results must be provided as part of the SSA authorisation process.

Research projects must address the extent to which the application fulfils the criteria of; reciprocity and community engagement; respect; equality; responsibility; survival and protection; and spirit and integrity in relation to research into the health of First Nations Australians in Metro South Health.

5.3 Data linkage

The [National best practice guidelines for data linkage activities relating to Aboriginal and Torres Strait Islander people 2012](#) focuses on six key aspects of data linkage. These are the values and ethics in human research relating to Aboriginal and Torres Strait Islander peoples, transparency and accountability, the quality of the Indigenous status variable on key data sets, the quality of the variables that are used for the linkage, the quality of the linkage itself, and the methods and algorithms used to derive Indigenous status where Indigenous status varies across the individual data sets in the linked data set.

Accurate data about Aboriginal and Torres Strait Islander peoples are needed to guide policy formulation, program development and service delivery, towards closing the gap in disadvantage and life expectancy between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians.

5.4 Data sovereignty

Data sovereignty is a critical consideration when conducting research with Aboriginal and Torres Strait Islander peoples. It pertains to the control and ownership of data and the rights of First Nations Communities.

- Recognise and respect the principle of First Nations self-determination. Aboriginal and Torres Strait Islander Communities should have the autonomy to determine how their data is collected, used, and managed in research projects that concern them.
- Clearly define and respect who owns and controls the data. Aboriginal and Torres Strait Islander peoples and individuals should have a say in data management and usage, and decisions regarding data should align with community preferences.
- Recognise the role of data custodians within Aboriginal and Torres Strait Islander Communities. Data custodians are often designated individuals or groups responsible for managing and protecting community data.
- Establish clear data access and sharing agreements with Aboriginal and Torres Strait Islander Communities. These agreements should outline who can access the data, for what purposes, and how it will be used.
- Implement robust data security and privacy measures to protect the confidentiality and integrity of Aboriginal and Torres Strait Islander data. This is especially important given the sensitive nature of some data.
- Respect First Nations cultural protocols for data use and dissemination, which may include restrictions on the use of certain data for particular purposes or by specific individuals.
- Consider the long-term management and archiving of research data, including who will be responsible for preserving and providing access to the data over time.

These aspects of data sovereignty are critical for respecting the rights, values, and cultures of Aboriginal and Torres Strait Islander peoples in research and ensuring that research benefits Indigenous Communities in a culturally sensitive and ethical manner.

RESPONSIBILITIES

Position	Responsibility	Audit criteria
MSH Consumer Partnering Team	<p>Provide education customised to specific needs of clinical and non-clinical services.</p> <p>Provide support in reviewing and evaluating systems, processes and services, and assist in the professional development of staff to ensure appropriate responses to Aboriginal and Torres Strait Islander needs.</p>	N/A
Metro South Research	Facilitate high quality research that will deliver improved health outcomes for all in our community.	N/A
Principal Investigator (PI)/ Coordinating Principal Investigator (CPI) - responsible officer	Engage in a culturally sensitive and respectful manner. This involves recognising and valuing Aboriginal and Torres Strait Islander knowledge, involving the community in the research process, prioritising cultural protocols, and ensuring that the research benefits the community while respecting rights and perspectives.	N/A

DEFINITIONS

Term	Definition
Co-investigator	An Aboriginal and Torres Strait Islander co-investigator in research is an individual from the First Nations Communities of Australia who actively collaborates with non-First Nations researchers on a research project. They hold a co-investigator role, contributing to the design, implementation, and interpretation of the research in a manner that aligns with Indigenous perspectives and priorities. Their involvement helps ensure cultural sensitivity,

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	community engagement, and the ethical conduct of research partnering with Aboriginal and Torres Strait Islander peoples.
Community	A group of people who share a common interest, such as cultural, social, political, health or economic interests, but who do not necessarily share a geographical location. Note that different types of Communities are likely to have different perspectives and approaches to research involvement.

RELATED AND SUPPORTING DOCUMENTS

Legislation and other Authority	<ul style="list-style-type: none"> • <i>Hospital and Health Boards Act 2011</i> (Qld) • <i>Hospital and Health Boards Regulation 2012</i> (Qld) • National best practice guidelines for data linkage activities relating to Aboriginal and Torres Strait Islander people (2012)
Standards	<ul style="list-style-type: none"> • National Clinical Trials Governance Framework • National Safety and Quality Health Service (NSQHS) Standards 2nd Ed. <ul style="list-style-type: none"> ○ Standard 1 – Clinical Governance ○ Standard 2 – Partnering with Consumers
Supporting documents	<p>Supporting resources - internal</p> <ul style="list-style-type: none"> • MSH Strategic Plan 2021-2025 • First Nations Health Equity Strategy 2022-2025 • Walking Tracks to Health Equity MSH Consultation Report 2022 • MSH Health Equity Final Yarning Circle Report 2022 • Health Equity Implementation Plan • PL2018-63 Health Equity • PR2018-180 Health Equity and Access Quality Improvement • Metro South Health Statement of Commitment to Reconciliation <p>Supporting resources - external</p> <ul style="list-style-type: none"> • Queensland Health Aboriginal and Torres Strait Islander Cultural Capability Framework 2010-2033 • Making Tracks Artwork and Protocols • Wilson, A. (2014). Addressing uncomfortable issues: reflexivity as a tool for culturally safe practice in Aboriginal and Torres Strait Islander health. <i>The Australian Journal of Indigenous Education</i>, 43(2), 218-230. • Harfield, S., Pearson, O., Morey, K. et al. Assessing the quality of health research from an Indigenous perspective: the Aboriginal and Torres Strait Islander quality appraisal tool. <i>BMC Med Res Methodol</i> 20, 79 (2020). https://doi.org/10.1186/s12874-020-00959-3

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Supporting MSH policy documents

Policies

- PL2019-64 Consumer Partnering

Procedures

- PR2021-285 Remuneration and reimbursement of consumer partners
- PR2019-186 Consumer partner orientation, onboarding and exit
- PR2023-411 Research excellence
- PR2023-412 Research support and management
- PR2023-413 Research administration and compliance

Work instructions

- WI2023-287 Research integrity
- WI2023-288 Research quality management systems
- WI2023-299 Data and privacy
- WI2023-290 Research authorship, peer review and publication
- WI2023-291 Research complaints and misconduct
- WI2023-292 Assessing and managing risk in research
- WI2023-299 Ethical and scientific review of research
- WI2023-301 Site specific assessment of research
- WI2023-297 Gift cards (for use as research incentives)

Guidelines

- GL2021-75 Partnering with consumers in research
 - GL2023-98 Research translation and impact
 - GL2023-99 Planning a research project
 - GL2021-77 Clinical trials
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HUMAN RIGHTS ACT 2019

Metro South Hospital and Health Service is committed to respecting, protecting, and promoting human rights. Under the *Human Rights Act 2019*, Metro South Health has an obligation to act and make decisions in a way that is compatible with human rights and, when making a decision, to give proper consideration to human rights. When making a decision about Aboriginal and Torres Strait Islander health research, decision-makers must comply with that obligation. Further information about the *Human Rights Act 2019* is available at: <https://www.forgov.qld.gov.au/humanrights>.

GUIDELINE DETAILS

Guideline Name	Aboriginal and Torres Strait Islander health research
Guideline Number	GL2023-97

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Current Version	1.0
Keywords	Research, First Nations Research, Aboriginal and Torres Strait Islander Research, Indigenous
Primary Document Reference	PL2023-92 Research Policy
Executive Sponsor	Chief People, Engagement and Research Officer
Endorsing Committee / Authority	Metro South Health Research Council
Document Author	Manager, Research Development, Metro South Research
Next Review Date	December 2026

REVIEW HISTORY

Version	Approval date	Effective from	Authority	Comment
1.0	7/12/2023	14/12/2023	Chief People, Engagement and Research Officer	New document