

National Health and Medical Research Strategy 2026-2036

Submission to the National Health and Medical Research Council (NHMRC)

Lowitja Institute, October 2025

National Health and Medical Research Council GPO Box 1421 Canberra ACT 2601

Dear NHMRC,

Re: Feedback on draft National Health and Medical Research Strategy Consultation

Lowitja Institute is Australia's national institute for Aboriginal and Torres Strait Islander health research, named in honour of our Patron, Dr Lowitja O'Donoghue AC CBE DSG.

Lowitja Institute is the only Aboriginal community-controlled research institute in Australia. We produce high-impact research, tools and resources that aim to have positive health outcomes for Aboriginal and Torres Strait Islander peoples, and our research is built on priorities that have been identified by Aboriginal and Torres Strait Islander people.

Lowitja Institute was established to centre our peoples within research, to ensure that research is no longer done on and about us; and instead advocate for and facilitate research don by us and for us. Based on this experience, we offer the following feedback on the draft National Health and Medical Research Strategy

Please find our submission attached. We would welcome the opportunity to further discuss any of the issues contained therein.

Warm regards

Rosemary Smith

Executive Manager of Policy and Consulting

Lowitja Institute

About Lowitja Institute

Lowitja Institute is a national Aboriginal and Torres Strait Islander community controlled health research institute, named in honour of its co-patron, the late Dr Lowitja O'Donoghue AC CBE DSG. Lowitja Institute works for the health and wellbeing of Australia's Aboriginal and Torres Strait Islander peoples by facilitating high-impact quality research and knowledge exchange, and by supporting a new generation of Aboriginal and Torres Strait Islander health researchers. Lowitja Institute engages in policy and advocacy work that contributes to a range of key policy debates related to Aboriginal and Torres Strait Islander health and wellbeing.

Feedback on the Draft National Health and Medical Research Strategy

We welcome the opportunity to provide written feedback to the NHMRC on the Draft National Health and Medical Research Strategy. This feedback echoes points raised by Lowitja Institutes CEO, Paul Stewart, during the first meeting of the Technical Reference Group - National Health and Medical Research Strategy, chaired by Ms Rosemary Huxtable AO PSM.

Key points of feedback we would recommend are considered are:

- 1. Structural inequities to research translation.
- 2. Access to funding and enabling initiatives.
- 3. Ethics as an enabler.
- 4. Indigenous Data Governance.

Structural inequities to research translation

Focus Area 3 states the need for removal of structural inequities to research translation for Aboriginal and Torres Strait Islander research to improve Aboriginal and Torres Strait Islander health outcomes, and address concerns raised around the need for longer-term, community-responsive funding.

It should be noted that there are other structural inequities for Aboriginal and Torres Strait Islander research beyond translation, including:

- Gaps Between Direct & Indirect Research Costs current funding often covers only direct research expenses, failing to account for infrastructure costs (e.g., facilities, equipment) and Indirect operational costs, such as administrative support and salaries.
- Ethical standards of research

 Access to funding – specifically, lack of access to funding for Aboriginal community-controlled organisations

Access to funding and enabling initiative

As outlined in Lowitja Institute's recent submission to the NHMRC on 'Research Priorities in Aboriginal and Torres Strait Islander Health 2025', Aboriginal and Torres Strait Islander researchers, and Aboriginal community controlled organisations (ACCO), face significant barriers and challenges in receiving research funding. Access to funding for Aboriginal and Torres Strait Islander peoples and organisations is critical, and key to this is reducing the level burden of funding criteria, to allow the ACCO sector to access much needed research dollars.

The draft Strategy includes a Funding Enabling Initiative, to assist in re-designing current funding mechanisms that channel funding for research across sectors.

This initiative should include a review of funding eligibility criteria and there is need for clearer and more detailed reporting about how Aboriginal and Torres Strait Islander research and researchers are funded.

Ethics as an enabler

It is important to acknowledge the role of ethics as a foundational element of a successful health and medical research ecosystem. Lowitja Institute has long advocated that all research related to Aboriginal and Torres Strait Islander communities must be ethical, and that it should benefit – rather than harm – those communities, and should be carried out with Aboriginal and Torres Strait Islander peoples' full, prior and informed consent.

Ethics approval processes in Aboriginal and Torres Strait Islander health exist to ensure that research involving Aboriginal and Torres Strait Islander people is conducted in an ethical and culturally appropriate manner. When ethics are not considered from Aboriginal and Torres Strait Islander perspectives, the analysis of a research projects risk and benefits is unlikely to adequately centre Aboriginal and Torres Strait Islander priorities, knowledges, cultural safety, or cultural and intellectual

¹ Lowitja Institute, 2025, 'Research priorities in Aboriginal and Torres Strait Islander Health 2025, Submission to the NHMRC September 2025, https://www.lowitja.org.au/wp-content/uploads/2025/09/NHMRC Research-priorities Lowitja-Institute.pdf

property.² To ensure that all Aboriginal and Torres Strait Islander knowledge, values and cultural safety are centred in all research projects involving our health and wellbeing, there is a critical need to embed Aboriginal and Torres Strait Islander research ethics processes – that are led by Aboriginal and Torres Strait Islander people.³

Considering the draft National Health and Medical Research Strategy flags enablers as the building blocks of a successful health and medical research ecosystem, it is critical to note the absence of ethics as an enabler. The need to streamline ethics, alongside grant funding, governance, data sharing and regulatory process was noted as a theme of the Phase 1 Consultations, but ethics has not been included as an enabler under this draft strategy.

Limited consideration of Indigenous data governance

Indigenous Data Governance (ID-GOV) is closely related to Indigenous Data Sovereignty (ID-SOV). It establishes processes and mechanisms for ensuring Indigenous peoples' rights and interests are reflected in data policies and practices.

Indigenous Data Governance enacts ID-SOV, providing processes and mechanisms for ensuring Indigenous Peoples' rights and interests are reflected in data policies and practices. It refers to the right of Indigenous peoples to autonomously decide what, how, and why Indigenous Data are collected, accessed and used. It ensures that data on or about Indigenous peoples reflects Indigenous priorities, values, cultures and worldviews, and diversity.⁴

Data sharing is strongly referred to throughout the Strategy, but there seem to be limited reference or consideration of data governance, and no reference to ID-GOV. In Australia we are seeing data practices being reconfigured to support Aboriginal and Torres Strait Islander communities and nations in accessing and sharing data, supported by Priority Reform 4 of the National Agreement on Closing

² Kennedy, M; Bryant, J, 2023, Ethics in Aboriginal and Torres Strait Islander health research, Lowitja Institute, Melbourne

³ Lowitja Institute, 2023, Policy Priorities, https://www.lowitja.org.au/wp-content/uploads/2023/11/LowitjaInstitute PolicyPriorities 2022-2025.pdf

⁴ Griffiths K.E., Johnston M., Bowman-Derrick S. 2021, Indigenous Data Sovereignty: Readiness Assessment and Evaluation Toolkit, Lowitja Institute, Melbourne, p.5

the Gap, which calls for 'shared access to data and information at a regional level'.⁵

Data sharing must be underpinned by strong Indigenous Data Sovereignty and Indigenous Data Governance principles. Lowitja Institute has consistently recommended that ID-SOV and ID-GOV be explicitly embedded in the *National Agreement on Closing the Gap*, and we acknowledge that ongoing conversations are taking place to secure this. To future proof the National Health and Medical Research Strategy, Lowitja Institute would strongly recommend that Indigenous Data Sovereignty and Indigenous Data Governance be included also.

⁵ Coalition of Aboriginal and Torres Strait Islander Peak Organisations and all Australian Governments, 2020, National Agreement on Closing the Gap, https://www.closingthegap.gov.au/national-agreement