LOWITJA INSTITUTE

Australia's National Institute for Aboriginal
and Torres Strait Islander Health Research

Research priorities in Aboriginal and Torres Strait Islander Health 2025

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

Lowitja Institute, September 2025

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

Dear NHMRC,

Re: Public call for research priorities in Aboriginal and Torres Strait Islander health

The 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.

The 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. 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 done by us and for us.**

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 the Lowitja Institute

The Lowitja Institute is a national Aboriginal and Torres Strait Islander Community Controlled Organisation working for the health and wellbeing of Australia's First Peoples through high impact quality research, knowledge translation, and by supporting Aboriginal and Torres Strait Islander health researchers.

Established in January 2010, we operate on the key principles of Aboriginal and Torres Strait Islander leadership, a broader understanding of health that incorporates wellbeing, and the need for the work to have a clear and positive impact.

At the Lowitja Institute our research is built on priorities identified by Aboriginal and Torres Strait Islander peoples. We aim to produce high impact research, tools and resources that will have positive health outcomes for Aboriginal and Torres Strait Islander peoples. To guide this, we work by five principles that underpin our approach to research. These principles are:

1. Beneficence – to act for the benefit of Aboriginal and Torres Strait Islander people in the conduct of our research.
2. Leadership by Aboriginal and Torres Strait Islander people
3. Engagement of research end users (Aboriginal and Torres Strait Islander organisations and communities, policymakers, other potential research users)
4. Development of the Aboriginal and Torres Strait Islander research workforce
5. Measurement of impact in improving Aboriginal and Torres Strait Islander people's health.

Based on this expertise we offer the following response.

General preamble

Aboriginal and Torres Strait Islander peoples and communities have long been the subjects of research, entrenched in a legacy of colonisation and unethical research practices. Since 1788, Euro-Western research practices have caused significant harm, erasure, and destruction to Aboriginal and Torres Strait Islander peoples, knowledges, and knowledge systems. Science and medical research have been strongly influenced by colonial ideologies and have caused significant harm; used as a tool of colonial violence, that contributed to the development of ideas of racial superiority and inferiority and unethical research practices.[1]

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[1] Lowitja Institute 2025, *Keeping Research on Tracking? Aboriginal and Torres Strait Islander Accounts of Ethical Conduct in Health and Medical Research,* Lowitja Institute, Melbourne

Research has historically been based on non-Indigenous researchers' priorities and presumptions, which did not and do not match the priorities of Aboriginal and Torres Strait Islander peoples. This meant that research often does not benefit Aboriginal and Torres Strait Islander peoples and findings have been – and continue to be – used to support policies and practices that further harmed us.[2] These poor research practices have caused significant mistrust from Aboriginal and Torres Strait Islander peoples and communities towards researchers and research institutions.[3]

It is important for us to highlight this history of research to contextualise our response within the history of colonisation, and its impact on our peoples' health and wellbeing.

Barriers and challenges faced by community controlled organisations in receiving research funding

There has been progress over recent years to ensure that research conducted by universities and mainstream research institutes and organisations is led by Aboriginal and Torres Strait Islander researchers and/or Aboriginal and Torres Strait Islander 'Chief Investigators', and within dedicated units. However, there is further need for reform to support Aboriginal and Torres Strait Islander community controlled led research – that is, research that is conducted primarily by Aboriginal and Torres Strait Islander people based on their own ways of knowing and doing, and within systems specifically for, and governed by, Aboriginal and Torres Strait Islander people.

Lowitja Institute continues to advocate for Aboriginal and Torres Strait Islander community controlled led research, as we know that when Aboriginal and Torres Strait Islander peoples are in control of research, and decision making, better outcomes will follow.

Aboriginal community controlled organisations (ACCOs) face multiple barriers to securing research funding, including:

- Not meeting the eligibility requirements for grant funding administered by bodies such as NHMRC and MRFF.

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[2] Lowitja Institute & MTP Connect, 2023, *Targeted Translation Research Accelerator Needs Assessment and Prioritisation Project*, discussion paper, Lowitja Institute

[3] AIATSIS and Lowitja Institute. 2013, *'Researching Right Way', Aboriginal and Torres Strait Islander Health Research Ethics: A domestic and international law review*¸ National Health and Medical Research Council

- Not being set up to undertake research and would require Board-approved changes to their constitutions to be able to meet NHMRC and MRFF eligibility requirements.
- Unlikely to have the research expertise, workforce, or economies of scale that universities and research institutes have which reduces significantly their ability to be competitive in grant rounds.
- Unlikely to have the necessary research infrastructure within their organisation, including capabilities to store and manage substantial amounts of data.
- Experiencing fatigue and feeling under-funded to perform all their critical functions and responsibilities.

The system that has been developed in Australia for research funding is inevitably much more responsive to universities and research institutes. It is not structured to be able to comprehend or respond to the need for Aboriginal and Torres Strait Islander community-controlled research even if policies and guidelines have been updated to promote greater involvement of Aboriginal and Torres Strait Islander people in research.

These barriers faced by ACCOs could begin to be addressed with the NHMRC implementing the *National Agreement on Closing the Gap* in full, within planning, policies and grant opportunity guidelines. This would go some way to ensuring that doors are opened for Aboriginal and Torres Strait Islander researchers and community controlled organisations to access much needed research dollars.

Lowitja Institute research priorities

At the Lowitja Institute our research is built on priorities identified by Aboriginal and Torres Strait Islander peoples. We aim to produce high impact research, tools and resources that will have positive health outcomes for Aboriginal and Torres Strait Islander peoples. 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. We regularly engage with Commonwealth, State and Territory governments, and Aboriginal and Torres Strait Islander mainstream peak bodies and professional associates, researchers and non-government organisations.

The guide the work of Lowitja Institute in shaping policy contexts that affect Aboriginal and Torres Strait Islander peoples, research and health systems, the Institute has a set of clear and consistent research and health policy priorities topics. Lowitja Institute identifies and pursues policy priorities that underpin and guide the work of Lowitja Institute in its research commissioning, knowledge translation, policy co-design and advocacy. The priorities are determined and led by Aboriginal and Torres Strait islander peoples, communities, researchers and experts.

Our 2022-25 policy priorities include:

Core Priorities	Emerging Priorities
Cultural safety in health policy and programs	Nation building for health and wellbeing
Climate change and health	Effects of a changing environment on housing access, adequacy and sustainability
Cultural and social determinants of health	Building capacity for good partnerships and codesign in health policy and programs
Racism in health systems	Understanding the effects of racism and adversity on biological systems
Ethics for Aboriginal and Torres Strait Islander health research	Data governance, infrastructure and sovereignty
	Building a culturally safe disability and aged care sector

We consistently advocate for and pursue research on our Aboriginal and Torres Strait Islander-led research priority areas, and they drive our approach policy and advocacy.

Emerging priorities areas for research in Aboriginal and Torres Strait Islander health

Lowitja Institute advocates for a series of priorities on research towards Aboriginal and Torres Strait Islander health. However, there are two emerging priorities that we wish to draw the NHMRC's attention to, that require sustained and consistent research funding.

GENOMICS

Genomics has significant potential to improve the health and wellbeing of Aboriginal and Torres Strait Islander peoples and address existing health inequalities. However, there are also significant risks associated with the use of genomics in health service delivery and research, not the least of which is the potential for increased experiences of racism and genetic discrimination of Aboriginal and Torres Strait Islander peoples.

The historical experiences involving unethical collection and use of Aboriginal and Torres Strait Islander genomic samples and data and negative eugenics, has led to a distrust of genomics and its applications in many Aboriginal and Torres Strait Islander communities. Discriminatory laws and policies based on disproved theories of race-based genetics have driven violent practices of colonisation and displacement of Aboriginal and Torres Strait Islander people. This historical experience, and the resulting mistrust, is often compounded by experiences of discrimination and racism in the contemporary health care system, including health research.

One of the reasons for the continued gap in health outcomes is that Aboriginal and Torres Strait Islander health researchers have rarely been supported or funded to lead research projects – the lack of available funding, and bias in funding decision-making and grant allocations, is a major barrier to the production of a meaningful health research that supports and empowers Aboriginal and Torres Strait Islander communities, and reflects our priorities.

For example, the under-representation of Aboriginal and Torres Strait Islander peoples in genomics research has led to several serious challenges, including blood transfusion complications. This under-representation means that Aboriginal and Torres Strait Islander peoples who need blood transfusions currently face a higher risk of immune reactions. Large-scale mapping of blood group variation in Aboriginal and Torres Strait Islander peoples, as is being undertaken by Professor Maree Toombs, a Euralayie/Kooma woman from the University of New South Wales, under a new $1.58 million grant from the ARC, which hopes to go some way to address this gap in blood group genetics, and benefit future Aboriginal and Torres Strait Islander communities who rely on safe blood supplies.[4] Importantly, this project will also focus on building Aboriginal and Torres Strait Islander capacity in genomics and developing a dedicated Aboriginal and Torres Strait Islander workforce to strengthen

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[4] Morse, C; 2025, 'Aboriginal professor to study Indigenous genomics data gap with support f ARC funding', 25 September, *National Indigenous Times*, https://nit.com.au/09-09-2025/20153/aboriginal-professor-to-study-indigenous-genomics-data-gap-with-support-of-arc-funding

community leadership in future research. More genomics research and investment in Aboriginal and Torres Strait Islander-led research is essential to addressing the broader gaps and exclusion of Aboriginal and Torres Strait Islander peoples in the area of genomics, and support Aboriginal and Torres Strait Islander peoples to have autonomy and sovereignty over their genomics data.

Aboriginal and Torres Strait Islander researchers and ACCHOs must be funded to engage in and lead research on genomics; this includes the provision of equitable, ethical and impact-driven investment in Aboriginal and Torres Strait Islander genomics research as part of existing and future genomics research funds.

ACQUIRED BRAIN INJURY AND FAMILY AND DOMESTIC VIOLENCE

Aboriginal and Torres Strait Islander women and children are at greater risk of family and domestic violence (FDV) and its consequences, and their symptoms and experiences are often overlooked or masked. Domestic violence causes disability for women through lasting impacts on their brains – a 2008 study from Adelaide found that Aboriginal women experience head injury, including traumatic brain injury to assault at 69 times the rate of non-Indigenous women.[5] Reported symptoms from Aboriginal and Torres Strait Islander women living with and managing traumatic/acquired brain injuries include:

- Memory trouble
- Dizziness and headaches
- Difficulty with concentration and organisation
- Trouble with taking in formation and thinking
- Finding it hard to start or keep conversations going with family and friends
- Mood swings and impulsivity[6]

Often referred to as an 'invisible disability', there is mass under reporting of traumatic/acquired brain injury for Aboriginal and Torres Strait Islander peoples, and a suit of health, wellbeing, economic and social consequences as a result.

Cultural bias and the impacts of racism when seeking medical treatment continue to impact the quality of care experienced by many Aboriginal and Torres Strait

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[5] Fitts, M; Wills, E; 2024, 'We need to better support First Nations women with violence-related brain injuries. Here's how', 22 August, *The Conversation*, https://theconversation.com/we-need-to-better-support-first-nations-women-with-violence-related-brain-injuries-heres-how-233329

[6] Fitts, M; Wills, E; 2024, 'We need to better support First Nations women with violence-related brain injuries. Here's how', 22 August, *The Conversation*, https://theconversation.com/we-need-to-better-support-first-nations-women-with-violence-related-brain-injuries-heres-how-233329

Islander people.[7] In addition to this, Aboriginal women often delay seeking help from services due to legitimate fears of child removal.[8] Both of these factors contribute to the under reporting and treatment of acquired/traumatic brain injury from family violence for Aboriginal and Torres Strait Islander women.

Aboriginal and Torres Strait Islander people with experiences of family and domestic violence who may or may not experience concurrent issues with alcohol and other drugs (AOD), often find that their symptoms are misidentified and attributed to their AOD use without appropriate consideration of possible acquired brain injury from physical violence.[9]

Much of the information of the experiences of First Nations women and children with disability, and First Nations women and children with experience of FDV, is not intersectional.[10] However, considering the wide ranging and often debilitating consequences of acquired brain injury on the lives and futures for Aboriginal and Torres Strait Islander peoples, investing in research on acquired brain injury and its links to family and domestic violence is essential if governments wish to meet all of the Targets outlined under the *National Agreement on Closing the Gap.*

There are significant gaps and understandings on research into the links between family and domestic violence and acquired brain injury. This is a serious issue, the full extent of which is not known, that requires immediate and substantial research investment.

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[7] Watego, C; Singh, D & Macoun, A; 2021, Partnership for Justice in Health: Scoping Paper on Race, Racism and the Australian Health System, Discussion Paper, The Lowitja Institute, Melbourne.

[8] Djirra, 2024, *Insights Report: Supporting a culturally responsive and accountable specialist family violence sector,* https://safeandequal.org.au/wp-content/uploads/REP_Insights-Report_Final-Word_v2.pdf

[9] Jones, J., Roarty, L., Gilroy, J., Brook, J., Wilson, M., Garlett, C., McGlade, H., Williams, R., Leonard, H. (2023). Research Report: Wangkiny Yirra "Speaking Up". First Nations women and children with disability and their experiences of family and domestic violence. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

[10] Ibid.