

Developing a Decadal Plan for Social Science Research Infrastructure 2023–32

Submission to the Academy of the Social Sciences in Australia

Response to: Doing social science in 2032: Charting national research infrastructure priorities – A discussion paper inviting input into the Academy's Decadal Plan for Social Science Research Infrastructure 2023–32

The Lowitja Institute, August 2023

1. About the Lowitja Institute

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. As an Aboriginal and Torres Strait Islander community-controlled organisation (ACCO), we work 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. We therefore welcome the opportunity to provide a submission to the Academy of the Social Sciences in Australia ('ASSA') regarding the development of a Decadal Plan for Social Science Research Infrastructure 2023–32 ('the Decadal Plan').

Established in 2010, the Lowitja Institute operates on a broad understanding of Aboriginal and Torres Strait Islander health that incorporates connection to family, community, culture and Country as fundamental to wellbeing. We are committed to Aboriginal and Torres Strait Islander control of the research agenda and to our work having a clear and positive impact, and accordingly, we invest in knowledge creation and translation by enhancing Aboriginal and Torres Strait Islander health research workforce capabilities.

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 key 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, and
- 5. **Measurement of impact** in improving Aboriginal and Torres Strait Islander people's health.

2. General preamble

The Lowitja Institute's work is underpinned by holistic approaches and understandings of the health and wellbeing of Aboriginal and Torres Strait Islander peoples and communities. We seek to support Aboriginal and Torres Strait Islander-led research that builds on a growing evidence base, demonstrating that the social and cultural determinants of health, climate and environmental changes, and justice in our health systems have significant impacts on the health and wellbeing of Aboriginal and Torres Strait Islander peoples.

We do this by directly commissioning research (via seed grants and major grants) so we can empower Aboriginal and Torres Strait Islander communities and organisations to transform their

ideas into aspirations that meet the needs of Aboriginal and Torres Strait Islander peoples and improve health and wellbeing outcomes within a generation. All of our grants are awarded to Aboriginal and Torres Strait Islander organisations – particularly ACCOs – and all grantees are provided with specific knowledge translation funding in order to ensure that their findings are socialised widely across their communities of practice and the broader research and policy landscapes.

The Lowitja Institute also builds research capability in our communities by awarding scholarships to support the next generation of Aboriginal and Torres Strait Islander leadership in health and wellbeing research. Our scholarships, which provide opportunities for Aboriginal and Torres Strait Islander students to develop and strengthen their research skills, have funded more than 160 students at all levels within the health and wellbeing research workforce. Further, we offer a number of tools and short courses to support research, workforce development, and service delivery work by both Aboriginal and Torres Strait Islander and non-Indigenous individuals and organisations.

We are, therefore, acutely aware of the critical importance of social science research infrastructures to Aboriginal and Torres Strait Islander peoples' and communities' wellbeing – particularly in designing, delivering, monitoring and evaluating effective public services. Research is an invaluable resource in supporting governments and ACCOs to work in partnership to achieve the goals and priorities of the National Agreement on Closing the Gap, and to ultimately see our communities having strong physical, social, emotional, spiritual and environmental wellbeing.

In our 2022 Federal Election Priorities¹, the Lowitja Institute called for the Australian Government to invest in:

- embedding Aboriginal and Torres Strait Islander research leadership,
- the recognition and implementation of the social and cultural determinants of health within policy and programs,
- the realisation of Indigenous data sovereignty and governance, and
- the development of the Aboriginal and Torres Strait Islander health and wellbeing research workforce, including by supporting the growth of the Aboriginal and Torres Strait Islander community-controlled research sector.

These remain our key priority infrastructures for the health <u>and</u> social science research sectors.

Based on our work and experience, we offer general comments and responses to the following questions highlighted in the Discussion Paper:

1. Producing, discovering and accessing data: Which needs can be met through improvements to existing assets, systems, rules or skills and training?

Lowitja Institute 2022, 2022 Federal Election Priorities. Available at: https://www.lowitja.org.au/content/lmage/Lowitja_ElectionPriorities_040522_D4.pdf

- 2. Producing, discovering and accessing data: Which needs require that the sector advocates for new assets, systems, rules or training?
- 3. Analysing data to generate new knowledge: Which needs can be met through improvements to existing assets, systems, rules or skills and training?
- 4. Analysing data to generate new knowledge: Which needs require that the sector advocates for new assets, systems, rules or training?

In addressing these questions, we have also considered other research infrastructures that require significant long-term investment, including Indigenous research ethics and knowledge translation to maximise research impact.

3. Indigenous data sovereignty and governance

Indigenous data sovereignty (ID-SOV) is a growing field of scholarship with important implications for research, policy development and public service delivery pertaining to First Peoples across the world. In Australia, the Mayam nayri Wingara Indigenous Data Sovereignty Collective defines ID-SOV as the right of Aboriginal and Torres Strait Islander peoples to exercise ownership over Indigenous data (being information or knowledge, in any format or medium, which is about and may affect our peoples both collectively and individually). Ownership of such data can be expressed through its creation, collection, access, analysis, interpretation, management, dissemination and reuse.

ID-SOV is practiced through Indigenous data governance (ID-GOV) – the right of Aboriginal and Torres Strait Islander peoples to autonomously decide what, how and why Indigenous data is collected, accessed and used, thus ensuring that data about our peoples reflects our priorities, values, cultures, worldviews and diversity. ID-SOV and ID-GOV are crucial prerequisites for our peoples and communities to be empowered to make decisions and shape policy based on our own goals and needs.

Accordingly, we advocate for stronger commitment by governments and mainstream institutions to ID-SOV and ID-GOV, including investment in the infrastructures needed for our communities to effectively collect, manage and share data. This is necessary to address the power imbalances and inequities that continue to be perpetuated by policymakers and those who control data ecosystems and infrastructure. Data is a powerful tool, and is at risk of being decontextualised or misused if ID-SOV and ID-GOV mechanisms are not in place. We see this in the oversupply of deficit-based data, which has created a discourse that sees Aboriginal and Torres Strait Islander peoples as problems – wholly responsible for inequities – rather than as resilient survivors of colonisation, genocide, racism and exclusion.

The Lowitja Institute's own work to advance ID-SOV includes the development of an Indigenous Data Sovereignty Readiness Assessment and Evaluation Toolkit for researchers, governments

and communities, released in 2022.² This toolkit provides a structure through which research organisations or teams can assess their readiness for ID-SOV via assessing the degree to which their systems and practices support Aboriginal and Torres Strait Islander people to control, develop, use, maintain and protect Indigenous data. The toolkit also supports users to monitor their progress over time and evaluate changes to their systems/practices in pursuit of ID-SOV.

Based on our significant experience working to support ID-SOV, we have some concerns that the Discussion Paper misconstrues ID-SOV as an individualist notion, based primarily on privacy rights and the principle of informed consent (for example, in Figure 4, p. 22, which states "Make Indigenous Data Sovereignty the gold standard for handling all human data: Eliminate double standards while setting the bar high for everyone"). It is important to note that, while privacy and informed consent are important elements of ID-SOV, so too is the origin of ID-SOV: in the advocacy of Indigenous and colonised peoples worldwide who are seeking to rebuild their nations and reassert their ownership of the stories that research and government data tell about them.

In other words, ID-SOV is grounded in the pursuit of self-determination, which takes place at the collective level of Aboriginal and Torres Strait Islander nations and other forms of community. **As such, we urge ASSA to reconsider the language used in reference to ID-SOV in the Discussion Paper.** Advocating for all people to have more control over their data privacy, and for all data collection or retention to require active informed consent, is a highly beneficial course of action that can be pursued without being tied to Aboriginal and Torres Strait Islander peoples' journey to achieve ID-SOV.

We also note that ACCOs continue to face significant barriers in accessing the relevant, granular, and strengths-based data that they need to carry out their research, evaluation, policy and service delivery work.³

Accordingly, we recommend that the Decadal Plan should advocate for the Commonwealth, State and Territory Governments to broaden and accelerate their implementation of the following data commitments under the National Agreement on Closing the Gap:

Priority Reform Four – Shared access to data and information at a regional level

72. Government Parties commit to implementing [the data and information elements laid out in Clause 71], including to:

a. share available, disaggregated regional data and information with Aboriginal and Torres Strait Islander organisations and communities on Closing the Gap, subject to meeting privacy requirements

² Griffiths K.E., Johnston M., & Bowman-Derrick S. 2021, Indigenous Data Sovereignty: Readiness Assessment and Evaluation Toolkit, Lowitja Institute, Melbourne.

³ Productivity Commission 2023, Review of the National Agreement on Closing the Gap: Draft Report, Productivity Commission, Canberra; Productivity Commission 2023, Review of the National Agreement on Closing the Gap: Priority Reform 4 – Shared access to data and information at a regional level, Information paper 5, Productivity Commission, Canberra.

- b. establish partnerships between Aboriginal and Torres Strait Islander people and government agencies to improve collection, access, management and use of data, including identifying improvements to existing data collection and management
- c. make their data more transparent by telling Aboriginal and Torres Strait Islander people what data they have and how it can be accessed
- d. build capacity of Aboriginal and Torres Strait Islander organisations and communities to collect and use data.
- 73. Government Parties will include in their annual reports information on action taken to improve access to data and information by Aboriginal and Torres Strait Islander people and organisations.
- 74. By 2023, the Parties will establish data projects in up to six locations across Australia to enable Aboriginal and Torres Strait Islander communities and organisations to access and use location-specific data on the Closing the Gap outcome areas.
- 75. The data projects will:
 - a. support Aboriginal and Torres Strait Islander communities to analyse and use regional specific data to help drive their own development and discussions with governments on Closing the Gap
 - b. enable Aboriginal and Torres Strait Islander communities and organisations to collect and access other data which they consider important
 - c. be covered by localised agreements, consistent with Priority Reform One, between the governments and participating Aboriginal and Torres Strait Islander organisations in the region.⁴

Further, we recommend that the Decadal Plan should amplify our calls for:

- all governments to urgently review State, Territory and national policies and guidelines that limit data-sharing and hinder timely access to administrative and survey data that must inform Aboriginal and Torres Strait Islander-led decision-making; and
- the Australian Government to support the development of a purpose-built Indigenous Wellbeing Index a central national source of evidence that would provide researchers and policymakers with consistent, comparable data on the wellbeing of Aboriginal and Torres Strait Islander people and communities. As a 'single source of truth' with ID-SOV embedded by design, this Index would enable access to richer data to design, implement and evaluate programs that work for people in the places they live. It would also support the development of local and regional data profiles, maximise the effectiveness of investments in research and programs, and could powerfully and credibly influence future policy development.

Focus on capability-building

There is an urgent need for governments and mainstream research institutions to make long-term investments in developing their own capabilities, and those of Aboriginal and Torres Strait

⁴ Joint Council on Closing the Gap 2020, *National Agreement on Closing the Gap*, Department of the Prime Minister and Cabinet (Australian Government), Canberra.

Islander communities and researchers, to uphold the principles of ID-SOV and undertake data development. As the above excerpt shows, data workforce development and capacity-building are critical to accurately assessing progress against the National Agreement on Closing the Gap.

The Lowitja Institute recommends that the Decadal Plan should call for:

- all governments and mainstream research institutions to undertake training and ongoing self-assessment in their implementation of ID-SOV
- all governments to fund ACCOs to undertake training in quantitative/statistical data analysis and qualitative research.

4. Ethical research with Aboriginal and Torres Strait Islander peoples

To ensure that 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 leadership in research ethics processes. Yet there remains no standalone national Aboriginal and Torres Strait Islander health research ethics committee, despite our peoples being the subjects of ever-growing amounts of research, and even as the critical importance of Indigenous Data Sovereignty has been acknowledged by increasing numbers of stakeholders.

When research ethics are not considered from Aboriginal and Torres Strait Islander perspectives, the analysis of a research project's risks and benefits is unlikely to adequately centre Aboriginal and Torres Strait Islander peoples' priorities, knowledges, cultural safety, or cultural and intellectual property. As a result, the benefits of such research do not accrue equally to the Aboriginal and Torres Strait Islander research participants, and their communities, as they do to the researchers and academic institutions involved. The conduct of the research itself may even be harmful to the Aboriginal and Torres Strait Islander participants.

The Lowitja Institute holds as one of its core principles that research involving Aboriginal and Torres Strait Islander peoples <u>must</u> be of beneficence to Aboriginal and Torres Strait Islander peoples. Accordingly, we have identified a significant opportunity to establish a national Aboriginal and Torres Strait Islander Health Research Ethics Committee (HREC), registered with the National Health and Medical Research Council (NH&MRC).⁵

Given that the Aboriginal and Torres Strait Islander concept of health is broad – including physical, social, emotional, environmental and spiritual wellbeing – this HREC would play a major role in safeguarding quality and ethical standards in not only health research, but also

⁵ For more detail and information on further initiatives needed to maximise the effectiveness of the proposed Aboriginal and Torres Strait Islander HREC, please see the forthcoming discussion paper: Kennedy M. & Bryant J. 2023, Ethics in Aboriginal and Torres Strait Islander Health Research – Discussion Paper, Lowitja Institute, Melbourne. This paper will be published on the Lowitja Institute website: www.lowitja.org.au.

social science research, that aims to improve Aboriginal and Torres Strait Islander wellbeing over the next decade. We urge ASSA to support this HREC as a key new infrastructure for producing, discovering, and accessing data, and for analysing data to generate new knowledge.

5. Knowledge translation to research impact for empowerment

It has now been almost a decade since the NH&MRC initiated its 'evidence-practice/policy gaps' project, which aimed to facilitate more effective allocation of funding to the areas of greatest need in Aboriginal and Torres Strait Islander wellbeing, and to encourage the development of more effective health services, guidelines and policies. Research impact (generally understood as referring to the contribution research makes to the economy, society, public policy or health that is beyond contributions to academia) is also an emerging national requirement of government-funded research projects.

However, the lack of progress against several Closing the Gap targets⁸ – despite an abundance of Aboriginal and Torres Strait Islander-led research highlighting the solutions – is a clear signal that there is still a gap between research evidence, policymaking, and practice. This gap is concerning and indicates that wellbeing improvements are limited not by lack of evidence or knowledge, but by failure to apply this knowledge into practice. This indicates a strong case for an increased emphasis on how knowledge is currently being translated – as opposed to how it can or ought to be translated – to produce impact in the context of Aboriginal and Torres Strait Islander peoples' wellbeing.⁹

Knowledge translation refers to a complex and reciprocal series of interactions between knowledge holders, knowledge producers, and knowledge users, with the goal of achieving research impact – positive and sustainable long-term benefit for Aboriginal and Torres Strait Islander peoples, beyond the realm of academia. This reciprocal process of combining experiential wisdom with academic research underpins the Lowitja Institute's approach to knowledge translation as being not only the dissemination of research findings, but also the process of setting research priorities and developing research questions, selecting methodologies, and the collection and analysis of data. We advocate that effective knowledge translation must centre Aboriginal and Torres Strait Islander communities and their wisdoms throughout in order to achieve maximum research impact, and must be implemented

⁶ National Health and Medical Research Council (NH&MRC) 2021, Evidence-Practice Policy Gap, National Health and Medical Research Council (Australian Government), Canberra.

⁷ Australian Research Council (ARC) 2012, Research Impact Principles and Framework. Available at: https://www.arc.gov.au/about-arc/strategies/research-impact-principles-and-framework

Productivity Commission 2023, Review of the National Agreement on Closing the Gap: Draft Report, Productivity Commission, Canberra; Productivity Commission 2023, Closing the Gap Annual Data Compilation Report July 2023, Productivity Commission, Canberra.

⁹ Lowitja Institute 2020, Knowledge Translation to Research Impact for Empowerment: Policy Position Paper, Lowitja Institute, Melbourne.

through a carefully designed process that minimises power dynamics and privileges Aboriginal and Torres Strait Islander perspectives.

Knowledge translation and research impact are particularly important for research on Aboriginal and Torres Strait Islander peoples' wellbeing, given the long history of research being done on Aboriginal and Torres Strait Islander communities, rather than by, for, and with Aboriginal and Torres Strait Islander peoples. Past research has often treated Aboriginal and Torres Strait Islander people as passive subjects rather than active participants, and as a result, failed to translate findings into meaningful change in policies, programs, or the ultimate wellbeing of Aboriginal and Torres Strait Islander peoples.

The Lowitja Institute is the only known Aboriginal and Torres Strait Islander research institute in Australia that explicitly funds knowledge translation, and our 'Knowledge Translation to Research Impact for Empowerment Approach' is the first of its kind that incorporates Aboriginal and Torres Strait Islander health research principles together with knowledge translation and research impact. The Approach aims to achieve positive health outcomes and wellbeing for Australia's First Peoples by creating impact-literate individuals and research culture. It is underpinned by the philosophy that effective health research requires a process that reflects community priorities and earns trust and community engagement.¹⁰

Our Knowledge Translation to Research Impact for Empowerment Approach calls for governments and mainstream research institutions to undertake the following actions, which we urge ASSA to include in the Decadal Plan:

- Prioritise investment in evidence-informed approaches to Aboriginal and Torres Strait Islander health and wellbeing.
- Require impact-based evaluation of existing health and wellbeing research investments.
- Policy and research in Aboriginal and Torres Strait Islander health and wellbeing must invest in, and require the inclusion of, Indigenous knowledges and perspectives.
- Develop research inclusion measures that reflect Aboriginal and Torres Strait Islander research principles and protocols.
- All research in Aboriginal and Torres Strait Islander health and wellbeing should include dedicated funding for knowledge translation activities.
- All health and wellbeing researchers should be required to access training and development in knowledge translation and research impact.

¹⁰ Ibid.