

Indigenous Data Sovereignty

Policy Brief

April 2023


Introduction

Lowitja Institute, as Australia's national institute for Aboriginal and Torres Strait Islander health research, works 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. In doing so, Lowitja Institute aims to increase the quality and quantity of Aboriginal and Torres Strait Islander health research and ensure that it reflects the priority needs of Aboriginal and Torres Strait Islander peoples. Data is central to achieving this goal.

Data is the information collected during research and is a valuable resource and a cultural, strategic, and economic asset for Aboriginal and Torres Strait Islander peoples.¹ There has been an emerging and urgent need to address how data is collected and used in ways that shift ownership and control for the benefit of Aboriginal and Torres Strait Islander peoples, acknowledging the need for Aboriginal and Torres Strait Islander to exercise self-determination over their knowledges, data and cultures.

History of data

Colonial practices relating to data have impacted and continue to negatively impact Aboriginal and Torres Strait Islander peoples and communities.² Research has too often been done 'on' rather than 'for' or 'by', Aboriginal and Torres Strait Islander peoples and communities. It was used to cause harm through historical protection and assimilation policies and continues to be interpreted through a deficit discourse.^{3,4} Within the dominant culture, what is measured is what matters. Ongoing institutional racism, systemic discriminations and ingrained biases continue to dismiss the priorities of Aboriginal and Torres Strait Islander people within organisations and systems, and devalue our peoples' priorities, which includes data practices.



Historically, data development and analysis has occurred in mainstream systems that held dominant cultural viewpoints and their own ways of interpreting data – the echoes of this practice remain with us. Aboriginal and Torres Strait Islander peoples were isolated from this process and unable to benefit from their own data. It is important to understand that colonial and neo-colonial practices continue to impact Aboriginal and Torres Strait Islander data. Unethical research practices in the past have included unethical data use. As *Maiam nayri Wingara* notes:

This has resulted in data that are overly focused on Indigenous peoples as the problem. Existing data and data infrastructure do not recognise or privilege Aboriginal and Torres Strait Islander knowledges and world views nor meet their current and future needs.⁵

Deficit-based data

The oversupply of deficit-based data has created a discourse that sees Aboriginal and Torres Strait Islander peoples presented as a problem. Known as deficit discourse, this refers to a mode of thinking that frames and represents Aboriginal and Torres Strait Islander people in a narrative of negativity, deficiency, and failure.⁶ This discourse has been identified as a significant barrier to improving health outcomes for Aboriginal and Torres Strait Islander people; the over-supply of deficit health data and statistics and the discourse that accompanies this data pervades the political and social climate. It works to inform policy makers and practitioners in the development of policies and programs that are disempowering for Aboriginal and Torres Strait Islander people.

Deficit discourse and deficit-based data undermines the development of solutions that are empowering and led by Aboriginal and Torres Strait Islander peoples and communities, who ultimately are the ones who know what is best for their communities. Leadership and self-determination are critical to addressing the disparities in health; Aboriginal and Torres Strait Islander peoples must have control and ownership over the data that relates to them and their communities. This will assist in disengaging from deficit discourse and shifting towards strengths-based approaches, which seek to move away from the traditional problem-based paradigm and offer a different language and set of solutions to overcoming certain issues⁷.

Ethical data collection and use, including with Aboriginal and Torres Strait Islander peoples having control and ownership over how data is produced and used, is critical to this shift towards strengths-based models and approaches. To achieve this,



Aboriginal and Torres Strait Islander peoples must have sovereignty and governance over the use of data pertaining to them.

Indigenous Data Sovereignty and Indigenous Data Governance

Indigenous Data Sovereignty (ID-SOV) and Indigenous Data Governance (ID-GOV) are central to comprehensive and ethical data collective that supports Aboriginal and Torres Strait Islander people's rights to govern their own data, including its creation, collection, and use, in line with self-determination.

Indigenous data refers to information or knowledge, in any format or medium, which is about and may affect Indigenous peoples both collectively and individually.⁸

Indigenous Data Sovereignty or (ID-SOV) refers to the inherent and inalienable rights relating to the collection, ownership, and application of data about Indigenous peoples, and about their lifeways and territories.

This includes Indigenous peoples' right to maintain, control, protect and develop their cultural heritage, traditional knowledge, and traditional cultural expressions, as well as their right to maintain, control, protect and develop their intellectual property over these.

Indigenous Data Governance or (ID-GOV) 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, worldviews, and diversity.

Indigenous data sovereignty in practice

ID-SOV is enshrined in the United Declaration of the Rights of Indigenous Peoples (UNDRIP). In Australia, it means that Aboriginal and Torres Strait Islander peoples have the right to determine what happens with data that is about them and/or they have directly provided.

This includes how data is:



ID-SOV is aligned with Aboriginal and Torres Strait Islander peoples' collective sovereign rights to govern their own communities, resources, and Country in line with our unique ways of knowing, being and doing.⁹

Aboriginal and Torres Strait Islander peoples had existing data processes and ecosystems prior to colonisation. They know best how to utilise data for the benefit of individual and community health and wellbeing. ID-SOV is intrinsically linked to Aboriginal and Torres Strait Islander community control, leadership and self-determination, and is fundamental to ethical research.

ID-SOV and ID-GOV contributes to empowering Aboriginal and Torres Strait Islander peoples and communities to make decisions and shape policy based on our own priorities and goals. Therefore, Aboriginal and Torres Strait Islander peoples are advocating for a stronger commitment by governments and mainstream institutions to ID-SOV and ID-GOV, and a greater understanding of what they mean. This can address and prevent the power imbalances and inequities that continue to be perpetuated by policy makers and those that control data ecosystems and infrastructure.¹⁰

Aboriginal and Torres Strait Islander experts have been leading national and international conversations around data sovereignty theory and practice. They include Professor Ray Lovett, Dr Maggie Walter, and Dr Kalinda Griffiths, alongside NACCHO and ACCHO Affiliates and other Aboriginal and Torres Strait Islander peak organisations. Increasingly, communities are engaging in community data projects and Aboriginal and Torres Strait Islander organisations are considering how to strengthen self-determination and community control through ID-SOV.

Universities and researchers also have a large role to play. In 2021, Lowitja Institute released the *Indigenous Data Sovereignty Readiness Assessment and Evaluation Toolkit* for researchers.¹¹ This toolkit demonstrates that ID-SOV is something that can

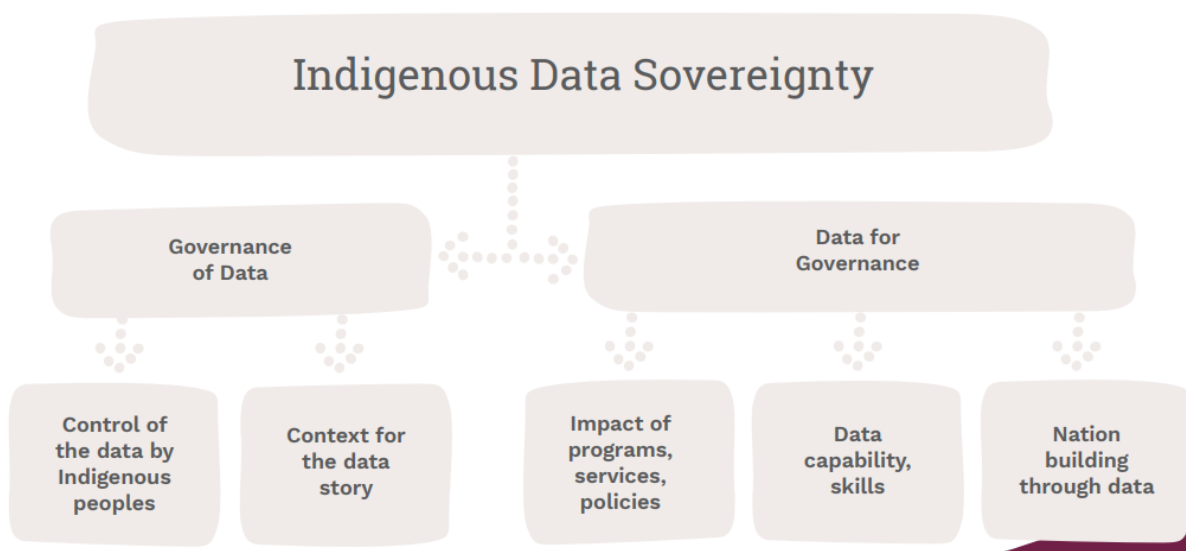
be evaluated and measured within organisations and describes practical steps that can be taken at individual, organisational, policy and governmental levels to strengthen ID-SOV and ID-GOV.

Implementing Indigenous Data Governance

ID-GOV is the practical activation mechanism for implementing ID-SOV.¹² As stated in the *Maiaṃ nayri Wingara* Communique following the 2018 *Indigenous Data Sovereignty Summit* in Canberra:

*Exercising Indigenous Data Governance enables Indigenous peoples, our representative and governing bodies to accurately reflect our stories. It provides the necessary tools to identify what works, what does not and why. Effective Indigenous Data Governance empowers our peoples to make the best decisions to support our communities and First Nations in the ways that meet our development needs and aspirations.*¹³

The diagram below from the *Indigenous Data Sovereignty Readiness Assessment and Evaluation Toolkit*¹⁴ explains the two components of ID-GOV. The first on the left is the **governance of Indigenous data**. The second on the right is the **use of data for governance** of policy, programs, systems, as well as data workforce development and capability, and supporting Indigenous nation building through data.¹⁵





Maiam nayri Wingara outline key protocols and principles for Indigenous Data Governance. They are Aboriginal and Torres Strait Islander peoples' rights to:

1. Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.
2. Data that is contextual and disaggregated.
3. Data that is relevant and empowers sustainable self-determination and effective self-governance.
4. Data structures that are accountable to Indigenous peoples and First Nations.
5. Data that is protective and respects our individual and collective interests.¹⁶

These protocols and principles can be translated into effective and actionable steps to transfer control of data ecosystems to Aboriginal and Torres Strait Islander peoples or enable their leadership in the development of new ones. It is important that Governments support this through actions such as:

- ⌚ Commit funding and resources to systemic reform to facilitate data sovereignty.
- ⌚ Support Aboriginal and Torres Strait Islander data projects and infrastructure.
- ⌚ Support Aboriginal and Torres Strait Islander leadership and control of the data ecosystem.
- ⌚ Support the development and growth of specialist capabilities in data navigation and epidemiology within the Aboriginal and Torres Strait Islander workforce.
- ⌚ Increase ambition regarding the *National Agreement on Closing the Gap Priority 4*, including specifically naming ID-SOV as an underlying principle of the National Agreement.

The National Agreement on Closing the Gap

The *National Agreement on Closing the Gap* (the National Agreement) Priority Reform 4 focuses specifically on data and contributes to a further target listed in Clause 87 that was to be developed within three months of signing the agreement:

⌚ **Priority Reform 4** – Shared Access to Data and Information at a Regional Level:

- **Target:** Increase the number of regional data projects to support Aboriginal and Torres Strait Islander communities to make decisions about Closing the Gap and their development.

⌚ **Clause 87 – Access to information:** This target will measure Aboriginal and Torres Strait Islander people's access to the information and services participation in informed decision-making about their lives. This will require data development to measure digital inclusion, including ability to use the internet at home and in the community; accessibility of different online services; and the availability and use of culturally relevant media.

THE CENTRALITY OF DATA TO IMPLEMENTING THE NATIONAL AGREEMENT ON CLOSING THE GAP

The Lowitja Institute has a longstanding commitment to the *National Agreement on Closing the Gap*, notably Priority Reform 4: Shared Access to Data and Information at a Regional Level and has advocated for the explicit inclusion of Indigenous Data Sovereignty (ID-SOV) within the National Agreement.


To measure progress against the National Agreement at a national scale requires significant data infrastructure and organisation. A task of this size demands comprehensive and consistent data collection processes and is critical to increasing accountability across the whole of government.

Given the centrality of data to monitoring progress against the National Agreement and its Priority Reforms and associated socio-economic targets, data collection must adhere to the principles of Indigenous Data Sovereignty (ID-SOV) and Indigenous Data Governance (ID-GOV) and the Lowitja Institute has called for Indigenous Data Sovereignty to be explicitly included within the National Agreement to support this.

Aboriginal and Torres Strait Islander communities have been asking for data sovereignty and proper meaningful implementation of the National Agreement for some time and have called on governments to uphold their commitments to the National Agreement to both gather and share data on its progress.

National Aboriginal and Torres Strait Islander Health Plan 2021-2023

The *National Aboriginal and Torres Strait Islander Health Plan 2021-2023*¹⁷ (the Health Plan) guides all action, including policies and programmes designed to improve



health and wellbeing outcomes for Aboriginal and Torres Strait Islander people. The plan was developed in partnership with Aboriginal and Torres Strait Islander people, and takes a strengths-based approach that acknowledges the cultural and social determinants of health.

ID-SOV and ID-GOV are in the Health Plan as a feature of the accountability framework and in these two objectives:

- ⊗ **Objective 12.1** – Establish governance structures and partnerships to guide how Aboriginal and Torres Strait Islander health data is collected, shared, and used, including at the regional level.
- ⊗ **Objective 12.2** – Develop culturally relevant metrics to track health and wellbeing.

Workforce and capacity building

Growing and supporting the Aboriginal and Torres Strait Islander workforce is crucial to improving the health and wellbeing of Aboriginal and Torres Strait Islander peoples. Moreover, building the capacity of the research sector in Aboriginal and Torres Strait Islander data is critical ID-SOV and ID-GOV – this includes building the Aboriginal and Torres Strait Islander workforce in data use, building the capacity of individuals and organisations across a range of ID-SOV and ID-GOV components, developing mechanisms that support Aboriginal and Torres Strait Islander leadership, and ensuring that Aboriginal and Torres Strait Islander people are engaged at every stage of a project that involves Aboriginal data¹⁸.

Data literacy is a further consideration that is essential for individuals and communities and the health research workforce. Data literacy in the Aboriginal and Torres Strait Islander health research setting is related to the capabilities of individuals and organisations to appropriately and accurately design, collect and use data pertaining to Aboriginal and Torres Strait Islander people. ID-SOV and ID-GOV require Aboriginal and Torres Strait Islander peoples, communities and researchers to be data literate, and measures that support increasing the data workforce.¹⁹

The *National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework 2021–2031* (National Workforce Plan) makes specific commitments about Aboriginal and Torres Strait Islander health workforce data:

- ⊗ **Strategic Direction 6** – Information and data are provided and shared across systems to assist health workforce planning, policy development, monitoring and evaluation, and continuous quality improvement.

ABOUT THIS POLICY BRIEF

This paper provides summary of the definition of Indigenous data sovereignty and an introduction to Indigenous data sovereignty in practice.

For more information, please contact admin@lowitja.org.au

Suggested citation: Lowitja Institute 2023, Indigenous Data Sovereignty, Policy Brief, Lowitja Institute, Melbourne.

Published by Lowitja Institute, Melbourne, Australia



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

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¹⁴ K.E., Griffith, et. al., 2021.

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