LOWITJA INSTITUTE

Indigenous Data Governance and Sovereignty

This information sheet may be useful for Aboriginal and Torres Strait Islander peoples and organisations who are interested in research, thinking about being involved in research or have recently become involved in research.

What is data?

Data is the information collected during research. It may be expressed in numbers and measurements, known as quantitative data, or in words through descriptions of experiences and stories, known as qualitative data.

"'Indigenous data' refers to information or knowledge, in any format or medium, which is about, or may affect, Aboriginal and Torres Strait Islander peoples, collectively or individually"[1]. Aboriginal and Torres Strait Islander information or data should be treated and managed in these ways:

Reflect Aboriginal and Torres Strait Islander interests, values, and priorities, including cultural ways of knowing, being and doing.

Be collected with free, prior, and informed consent, including respect for confidentiality.*

Be returned in an easily understood and meaningful way.

Be used to advance self-determination and development.

Be accessible, appropriate, and meet Aboriginal and Torres Strait Islander needs.

Be stored securely.

Be interpreted by Aboriginal and Torres Strait Islander experts, ensuring it reflects Aboriginal and Torres Strait Islander lived experiences and perspectives.

Only be used how Aboriginal and Torres Strait Islander people, communities and organisations agree.

Free means no force, coercion, pressure, intimidation, or manipulation.

Prior means consent has been sought with enough time in advance of any agreement or commencement of activities for Indigenous consultations and consensus-building processes.

Informed means that all information relevant to the decision is provided about things like the place, size, scope and timing of a proposal, the reasons for it, its environmental impact, how it will be monitored and how benefits will be shared. Access to advisers, including legal counsel, is provided as needed"[9].

What is Indigenous Data Sovereignty?

Indigenous Data Sovereignty is the right of Aboriginal and Torres Strait Islander peoples, communities and organisations to maintain, control, protect, develop, and use data as it relates to us7. Indigenous Data Sovereignty describes how the rights of Indigenous peoples, our experiences, values and understanding are developed and reflected in any data and information gathered about us, our communities and our knowledges[7].

Indigenous Data Sovereignty is practiced through Indigenous data governance[6,7].

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> "The governance is about the management - who gets to determine, who gets to control, who has the capacity to ensure that the decisions that get made in relation to the governing of information and knowledge….are held and controlled by Indigenous populations."
>
> **Professor Daryle Rigney, Ngarrindjeri**

What is data governance?

As Aboriginal and Torres Strait Islander people and communities, we have the right to govern, retain control over, and manage the collection usage, and application of data for our purposes and to use it in ways that align with our self-determined priorities, aspirations and practices[5,7]. Strong governance ensures that data collection:

- supports the priorities of Aboriginal and Torres Strait Islander peoples, communities or organisations
- implements agreed standards for quality control
- helps ensure data is available in a timely way.

Why is it important to know about Indigenous data sovereignty and data governance in research?

In the past, research has too often been done 'on' rather than 'for' or 'by', Aboriginal and Torres Strait Islander peoples and communities.

This is achieved when research projects:

- are led by Aboriginal or Torres Strait Islander experts
- the team includes Aboriginal and Torres Strait Islander researchers
- the data that is collected reflects Aboriginal and Torres Strait Islander values and frameworks, such as cultural determinants of health[8].

Indigenous Data Sovereignty

Enables Aboriginal and Torres Strait Islander peoples to accurately reflect our stories, knowledges and experiences in research.

Empowers Aboriginal and Torres Strait Islander people to make the best decisions to support our communities in the ways that meet our needs and aspirations.

Research teams should consider the processes they use to collect, analyse and report on data in a culturally safe way, which reflect Aboriginal and Torres Strait Islander ways of knowing, being and doing[4]. This includes:

- effectively reporting on and returning data in a way that is respectful of and meaningful to Aboriginal and Torres Strait Islander peoples, communities and organisations
- negotiating what data is shared and how it is shared in a public manner, such as through reports and other publications, and how these recognise the contributions of Aboriginal and Torres Strait Islander knowledges.
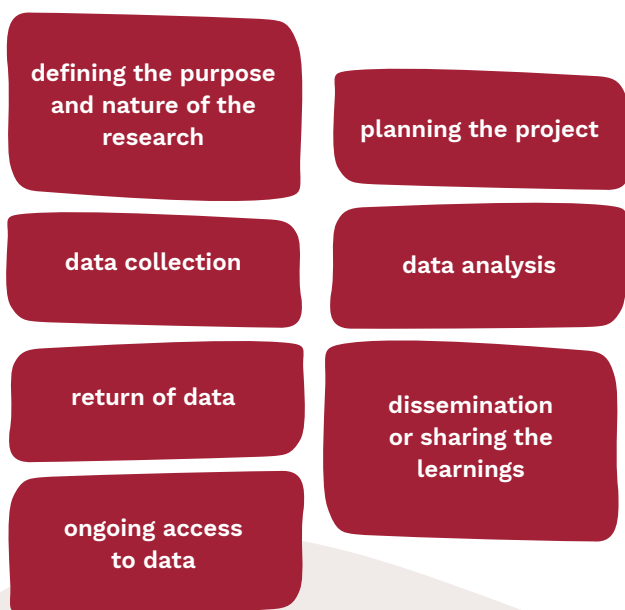
Indigenous Data Sovereignty requires all researchers, both Aboriginal and Torres Strait Islander and non-Indigenous, to actively engage with involved Aboriginal and Torres Strait Islander peoples, communities and organisations to ensure that the reporting of data reflects their priorities, values and cultures[6].

GOVERNANCE

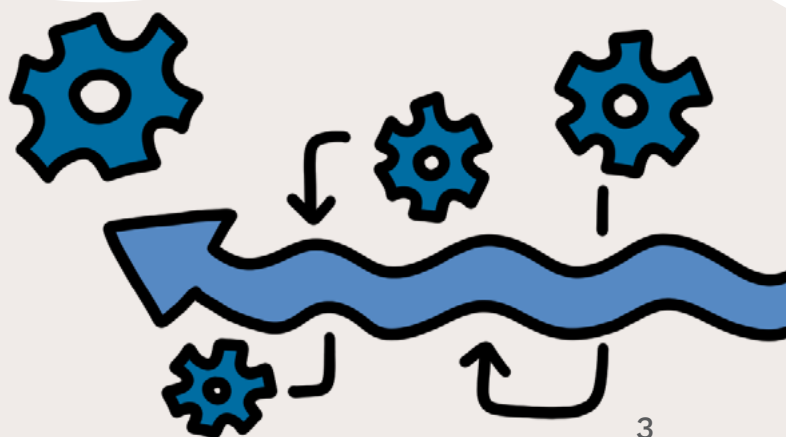## What are my rights with Indigenous Data Sovereignty and Data Governance in research?

Aboriginal and Torres Strait Islander peoples have the right to lead and/or participate at all stages of the research process and make decisions about the research process. This includes:[4]

- defining the purpose and nature of the research
- planning the project
- data collection
- data analysis
- return of data
- dissemination or sharing the learnings
- ongoing access to data

Before engaging in research, the research team must be conscious of these rights[4]. All researchers, both Aboriginal and Torres Strait Islander and non-Indigenous, should work with Aboriginal and Torres Strait Islander peoples, organisations, and communities to ensure that the research data reflects and benefits individual and collective interests.

Researchers should provide involved Aboriginal and Torres Strait Islander peoples, communities and organisations with the following[4]:

- appropriate information to promote your full and effective leadership in data collection,
- the opportunity to assess the data collection, storage, and governance of proposed research projects, including confidentiality,
- opportunities to engage in the development, design, collection analysis and reporting of data,
- involvement in the development of appropriate indicators and surveys so that it can be applied to your local contexts.

How can I protect my Indigenous Data Sovereignty rights when participating or leading research?

Aboriginal and Torres Strait Islander peoples have the right to decide how Indigenous data is used and stored. A formal agreement to protect Indigenous Data Sovereignty should be in place that covers:

- intellectual property rights
- data collection procedures
- retention, access to and management of all data arising from the research
- what actions Aboriginal and Torres Strait Islander peoples, communities and organisations can take if a research team does not meet the commitments in the agreement[5].

The agreement should be clearly understood and formally endorsed by appropriate representatives of the Aboriginal and Torres Strait Islander peoples, communities and/or organisations involved[5].

Want to learn more:

- Indigenous Data Sovereignty (ID-SOV) Readiness Assessment and Evaluation Toolkit
- Read the An Evaluation Framework to Improve Aboriginal and Torres Strait Islander Health.
- Learn more about Indigenous Data Sovereignty on Maiam nayri Wingara website here

REFERENCES

1. Maiam nayri Wingara 2018, Indigenous Data Sovereignty: Key principles, Maiam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty Collective.

2. Kukutai, T. & Taylor J. (eds) 2016, Indigenous Data Sovereignty, ANU Press, Canberra. Available at:

3. National Health and Medical Research Council 2018, Keeping Research on Track II: A companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders, Commonwealth of Australia, Canberra.

4. Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) 2020, A Guide to applying The AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research, AIATSIS, Canberra.

5. Kelaher, M., Luke, J., Ferdinand, A., Chamravi, D., Ewen, S., & Paradies, Y. 2018, An Evaluation Framework to Improve Aboriginal and Torres Strait Islander Health Users Guide, The Lowitja Institute, Melbourne.

6. Maiam nayuri Wingara Indigenous Data Sovereignty Network & Australian Indigenous Governance Institute 2018, Indigenous Data Sovereignty, Briefing Paper.

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

8. Lowitja Institute 2020, Culture is Key: Towards cultural determinants-driven health policy – Final Report, Lowitja Institute, Melbourne. DOI: 10.48455/k9vd-zp46.

9. Australian Institute of Aboriginal and Torres Strait Islander Studies and Taungurung Land and Waters Council 2019, Taungurung Land and Waters Council Decision-Making Guide.