

Indigenous Data Sovereignty and Indigenous Data Governance

Frequently Asked Questions



Indigenous Data Sovereignty and Indigenous Data Governance are globally important for empowering Indigenous peoples and ensuring data about them and their lands is collected, managed and used in ways that respect sovereignty and self-determination.

This FAQ explains, in clear language for health researchers, the ethical principles and practical approaches to the creation, collection, management and use of data that support Aboriginal and Torres Strait Islander Peoples rights to govern their own data and exercise self-determination. It also signposts key Indigenous Data Sovereignty and Indigenous Data Governance resources from leading international and national organisations.

Why Indigenous Data Sovereignty and Governance Matter

Researchers play a critical role in shaping how data about Aboriginal and Torres Strait Islander peoples is collected, interpreted, stored and used. Engaging with Indigenous Data Sovereignty and Indigenous Data Governance is not an optional extra — it is a professional, ethical and responsibility. Indigenous Data Sovereignty and Governance is fundamental to both ethical research practice and meaningful health outcomes. For researchers, it represents an essential ethical and legal obligation that shapes every stage of the research process. From building sustainable community partnerships, ethics approval and funding success that produce high-quality, relevant findings.

For Aboriginal and Torres Strait Islander Peoples, it is about self-determination: the right to control how data about their communities is collected, used, and interpreted. This control protects against historical harms, enables communities to define their own priorities, and ensures that research serves Aboriginal and Torres Strait Islander Peoples' interests rather than extracting knowledge without benefit.

In cancer research, where Aboriginal and Torres Strait Islander Peoples experience significantly poorer outcomes, Indigenous Data Sovereignty and Governance ensures that data becomes a tool for empowerment and health equity, not perpetuation of inequity.

Foundational Statements and Principles

What is Indigenous Data?

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

Indigenous data can include facts, statistics, research, storage, knowledge and records. It can be about people and communities, country – land, water, skies, environment, culture, health, education, employment, laws, governance and self-determination.

As an example, Indigenous data in a health research context may include both individual and collective/aggregated clinical data, genomic information, biospecimens, health records, cultural knowledge, and any information collected from or about Aboriginal and Torres Strait Islander Peoples.

What is Indigenous Data Sovereignty?

'Indigenous Data Sovereignty' refers to the right of Indigenous people to **exercise ownership** over Indigenous data. Ownership can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination and reuse of Indigenous data. These rights are based on the United Nations Declaration on the Rights of Indigenous People (UNDRIP)ⁱ and reflect in Priority Reform Four of the National Agreement on Closing the Gapⁱⁱ.

What is Indigenous Data Governance?

Indigenous Data Governance 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 their priorities, values, cultures, worldviews and diversity.



Why is this important for researchers?

As a researcher, understanding and implementing Indigenous Data Sovereignty is essential for:

Avoiding harm: Poor data practices can perpetuate stereotypes, breach privacy, cause cultural harm, and damage relationships between researchers and Indigenous communities for years to come.

Trust and participation: Historical research harms have created justified mistrust. Demonstrating genuine commitment to Indigenous Data Sovereignty builds trust, improves recruitment, and enables long-term community partnerships.

Research quality: Partnerships built on respect and self-determination lead to better research design, more meaningful outcomes, and findings that are relevant and useful to Indigenous communities.

Contributing to health equity: In cancer research, where Indigenous peoples experience significantly poorer outcomes, Indigenous Data Sovereignty and Governance ensures that data becomes a tool for empowerment and health equity, not perpetuation of inequity.

Ethics: It is the right thing to do. Indigenous peoples have inherent rights to self-determination and control over their data, recognised in the UN Declaration on the Rights of Indigenous Peoples (UNDRIP)ⁱ.

Legal and regulatory requirements: Australian research ethics frameworks, including NHMRC guidelines and AIATSIS Code of Ethicsⁱⁱⁱ, require adherence to Indigenous Data Sovereignty principles.

Funding: Funding bodies increasingly require Indigenous engagement strategies and Data Sovereignty protocols. Understanding and implementing these principles is becoming essential for competitive grant applications.

How and where do I start?

The **Maiam nayri Wingara** website (www.maiamnayriwingara.org) is a great resource that covers the history of the Indigenous Data Sovereignty and Indigenous Data Governance movement and has some great resources^{iv}.

For researchers in Victoria, the **marra ngarrgoo, marra goorri: The Victorian Aboriginal Health, Medical and Wellbeing Research Accord** positions Aboriginal and Torres Strait Islander People's cultures, worldviews, belief systems, and governance at the centre of the research process. The Accord provides guiding principles and lays out processes to be implemented to improve the ethical standards of health, medical and wellbeing research that impacts Aboriginal and Torres Strait Islander Peoples^v.

What are the Maiam nayri Wingara principles?

The Maiam nayri Wingara Indigenous Data Sovereignty Collective and the Australian Indigenous Governance Institute held an Indigenous Data Sovereignty Summit in Canberra on 20th June 2018. One of the main aims of the Indigenous Data Sovereignty Summit was to progress Indigenous Data Sovereignty and Indigenous Data Governance through developing shared understandings and initiating an Australian set of Indigenous Data Governance protocols and principles^{iv}.

The Maiam nayri Wingara Indigenous Data Sovereignty Collective developed principles that assert Aboriginal and Torres Strait Islander Peoples have the right to:

1. Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.

2. Data that are contextual and disaggregated (available and accessible at individual, community and First Nations levels).
3. Data that are relevant and empowers sustainable self-determination and effective self-governance.
4. Data structures that are accountable to Aboriginal and Torres Strait Islander Peoples and communities.
5. Data that are protective and respects our individual and collective interests.

How do these principles apply to research?

These principles mean that researchers must:

- Involve Aboriginal and Torres Strait Islander Peoples in all stages of research design and implementation.
- Establish governance structures that give Aboriginal and Torres Strait Islander communities control over their data.
- Ensure health and research data collection methods are strength-based, trauma-aware and healing-informed.
- Provide Aboriginal and Torres Strait Islander communities with access to research findings and data.
- Build accountability into research projects.

What should researchers do before handling, managing and/or analysing Indigenous data?

Researchers should apply the CARE Principles (Collective Benefit, Authority to Control, Responsibility, Ethics) for Indigenous Data Governance^{vi}. The CARE Principles, developed by The Global Indigenous Data Alliance, reflect the crucial role of data in advancing Indigenous innovation and emphasise ethical and culturally respectful data practices that prioritise Indigenous peoples' rights, interests, and self-determination.

The CARE principles are:

Collective Benefit: Data ecosystems shall be designed and function in ways that enable Indigenous peoples to derive benefit from the data.

Authority to Control: Indigenous peoples' rights and interests in Indigenous data must be recognised and their authority to control such data be empowered.

Responsibility: Those working with Indigenous data have a responsibility to share how those data are used to support Indigenous peoples' self-determination and collective benefit.

Ethics: Indigenous peoples' rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem.

The CARE Principles complement the existing FAIR Principles, which require data to be Findable, Accessible, Interoperable and Reusable. While the FAIR Principles are about making it easier to share and reuse data, the CARE Principles ensure that data is used ethically.

Where can I learn more?

Resources for further learning:

- **MaiaM nayri Wingara:** The MaiaM nayri Wingara Indigenous Data Sovereignty Collective^{iv}
- **Lowitja Institute:** Taking Control of Our Data: A Discussion Paper on Indigenous Data Governance for Aboriginal and Torres Strait Islander People and Communities^{vii}
- **marra ngarrgoo, marra goorri:** The Victorian Aboriginal Health, Medical and Wellbeing Research Accord^v
- **AIATSIS:** Ethics and research guidelinesⁱⁱⁱ
- **National Aboriginal Community Controlled Health Organisation (NACCHO):** Aboriginal and Torres Strait Islander Cancer Plan^{viii}
- **Cancer Australia:** Australian Cancer Plan and actions on Indigenous Data Sovereignty^{ix}
- **Global Indigenous Data Alliance (GIDA):** International perspectives and resources^x
- **Australian Indigenous Governance Institute (AIGI):** Indigenous governance resources^{xi}
- **Australian Research Data Commons:** Resources for FAIR and CARE Principles^{xii}



ⁱ United Nations, "United Nations Declaration of the Rights of Indigenous Peoples" (2007).

ⁱⁱ [National Agreement on Closing the Gap | Closing the Gap](#)

ⁱⁱⁱ <https://aiatsis.gov.au/research/ethical-research>

^{iv} www.maiamnayriwingara.org

^v <https://www.vaccho.org.au/accord/>

^{vi} <https://ardc.edu.au/resource/the-care-principles/>

^{vii} <https://www.lowitja.org.au/resource/taking-control-of-our-data-a-discussion-paper-on-indigenous-data-governance-for-aboriginal-and-torres-strait-islander-people-and-communities/>

^{viii} https://www.naccho.org.au/app/uploads/2024/02/NACCHO_CancerPlan_Oct2023_FA_online.pdf

^{ix} <https://www.australiancancerplan.gov.au/actions/4.2.4>

^x <https://www.gida-global.org/care>

^{xi} <https://aigi.org.au/>

^{xii} <https://ardc.edu.au/resource-hub/making-data-fair/>



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