

15 December 2023

Position Statement Indigenous Data Sovereignty



Vision

VACCHO recognises Aboriginal and Torres Strait Islander communities' right to manage the creation, collection, ownership, control, access, maintenance and application of data about Aboriginal and Torres Strait Islander peoples, Country, identity, culture, knowledge and practices, otherwise referred to as Indigenous Data Sovereignty (IDSov). IDSov enables communities to realise and benefit from the vast cultural, strategic and economic value that data holds for Aboriginal and Torres Strait Islander peoples.

Implementing IDSov will empower Aboriginal and Torres Strait Islander communities to autonomously conduct research, allowing them to define relevant health and wellbeing indicators and articulate desired outcomes from data collection and utilisation. This approach facilitates self-determination and contributes to the transformative enhancement of systems for the improved health and wellbeing of Aboriginal and Torres Strait Islander peoples. Central to this process is the imperative that data is controlled and returned to the respective communities it concerns.

Definitions

[Maiam nayri Wingara](#), the Australian Aboriginal and Torres Strait Islander Data Sovereignty Collective, held a summit in 2018 resulting in the following key definitions:

- **Indigenous Data:** information or knowledge, in any format or medium, which is about and may affect Indigenous peoples both collectively and individually.
- **Indigenous Data Sovereignty:** the right of Indigenous peoples to exercise ownership over Indigenous Data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination and reuse of Indigenous Data.
- **Indigenous Data Governance:** 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 our priorities, values, cultures, worldviews and diversity.

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Recommendations

RECOMMENDATION 1: The Victorian Government provide shared access to government data for Aboriginal Community Controlled Organisations (ACCOs) and communities and should publish disaggregated public data on Aboriginal peoples. The access to data should avoid developing an application process that places a high burden on Aboriginal and Torres Strait Islander communities in order for them to access their data from those who house it.

RECOMMENDATION 2: The Victorian Government should fund a capacity building program to provide opportunities for Aboriginal and Torres Strait Islander communities and ACCOs to create, collect, access, and govern their data.

RECOMMENDATION 3: The Victorian Government should embed IDSoV and Indigenous Data Governance (IDGov) definitions, principles and obligations, as expressed by Maïam nayri Wingara, in government frameworks, policies, and systems. This should also be included in the implementation activities required under the National Agreement on Closing the Gap.

RECOMMENDATION 4: The Victorian Government should ensure health and wellbeing service providers and organisations embed practices that uphold IDSoV and best-practice data protection, including the *CARE Principles for Indigenous Data Governance* and the *Aboriginal & Torres Strait Islander Data Archive Protocols*.

RECOMMENDATION 5: The Victorian Government should, with ACCOs, develop a mechanism to embed IDSoV and IDGov across the health and wellbeing sector so that IDSoV and IDGov arrangements are in place for funded activities, service agreements and joint projects involving Indigenous data and communities.

Background and Evidence

The marginalisation of Aboriginal and Torres Strait Islander peoples has been perpetuated and expressed through the exclusion of control over their data. Aboriginal and Torres Strait Islander peoples have long been excluded from decision-making surrounding the data collected about them, including why and how data is collected, use of their data, and what picture is presented.

This has been particularly prevalent in the Aboriginal Health and Wellbeing Sector, and there is an obligation to challenge historical arrangements with service providers, collectors and researchers that disregard the needs of Aboriginal and Torres Strait Islander communities and the wellbeing that is attached to data. There is a clear need for data, research and evidence to be Community owned and controlled as a key mechanism for realising self-determination.

Adopting the principles of IDSoV and obligations of IDGov instills and emphasises Aboriginal and Torres Strait Islander peoples' agency in controlling how their knowledge, and personal or sensitive information is used and accessed (Carroll et al, 2020). The implementation of IDSoV practices must also be in accordance with the recognition of Indigenous Cultural Intellectual Property and the free, prior and informed consent of the Aboriginal and Torres Strait Islander peoples concerned, as outlined in the *United Nations Declaration on the Rights of Indigenous Peoples*.

IDSoV and IDGov provides considerable protection against misuse of data, and acts as a key driver for self-determination. IDSoV also enables communities to authenticate Indigenous Knowledges and embed cultural restrictions on the access to data including access to sacred or secret information, Sorry Business or gender-based restrictions.

Under the *National Agreement on Closing the Gap*, all jurisdictions have committed to advancing capacity for data sharing amongst organisations and providing meaningful change in relation to Aboriginal Data Sovereignty as per Priority Reform 4. The current discussions create a platform for progressing the transparency and access of data and partnerships with communities.

The *Victorian Aboriginal Affairs Framework (2018-2023)* (VAAF) addresses these discussions, recognising that increased Aboriginal ownership and control of data is a key enabler of self-determination. The VAAF also recognises the importance of IDSoV foundations in strengthening Aboriginal advocacy, sector planning and

decision-making. Under Victoria's *Closing the Gap Implementation Plan (2021-2023)*, the Victorian government has committed to implementing existing Data Sovereignty commitments.

The Victorian *Self-Determination Reform Framework* echoes the VAAF's position on Aboriginal ownership and control of data in relation to self-determination. This Framework specifically targets the transfer of power and resources to communities as a necessary step in facilitating Indigenous self-determination, with a key action of supporting data sovereignty.

Ultimately, there is growing recognition of the notion and subsequent principles of IDSoV and obligations of IDGov. However, IDSoV and IDGov are yet to be formally adopted and implemented. This inhibits the facilitation and achievement of self-determination of Aboriginal and Torres Strait Islander peoples at a foundational level, preventing true Indigenous ownership, management and governance of the creation, collection, access and application of their data.

Therefore, more must be done to ensure effective Aboriginal and Torres Strait Islander control, management and governance of the creation, collection, access and application of their data. Alongside the recommendations outlined above, VACCHO supports the adoption of the Maiam nayri Wingara IDSoV techniques and principles:

- Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination, and infrastructure.
- Data that are contextual and disaggregated (available and accessible at individual, Community, and First Nations levels).
- Data that are relevant and empowers sustainable self-determination and effective self-governance.
- Data structures that are accountable to Indigenous peoples and First Nations.
- Data that are protective and respects our individual and collective interests.

A shared evidence base will assist in recognising the need for sharing and capturing data across and within the health system as a key enabler to creating a connected and holistic health system, requiring the access, use and application of data in a timelier manner for the benefit of Aboriginal and Torres Strait Islander communities, and in accordance with the wishes of Community.

References

Carroll, S. et al 2020, *The CARE Principles for Indigenous Data Governance*, 19 Data Science Journal.

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