

# Recognising Indigenous data sovereignty and implementing Indigenous data governance at the Ngangk Yira Institute for Change



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## Abstract

The concepts of Indigenous data sovereignty and Indigenous data governance have attracted a great deal of attention over the last two decades. There have been several international symposia and roundtable discussions on the subject and a larger number of books and articles have been published.

This paper focuses on developments in Australia, New Zealand, Canada and the United States of America, as countries with similar historical experiences, particularly in the relationship between the non-Indigenous colonisers and local Indigenous populations. Knowledge production related to Indigenous data sovereignty and data governance has direct relevance to the work of the Ngangk Yira Institute for Change (Ngangk Yira), Murdoch University – an Indigenous-led research intensive institute working in close collaboration with Aboriginal peoples and communities in Western Australia and nationally.

This paper discusses development of theoretical positions on Indigenous data sovereignty and the mechanism by which this can be achieved, namely: Indigenous data governance. The variety of models, frameworks and principles are then examined. It also describes current projects being undertaken to assist Indigenous communities exercise sovereignty over their data and provides some examples of what can be achieved when research privileges an Indigenous world view and focuses on issues important to Indigenous people and communities. Finally, it explains how Ngangk Yira is incorporating the principles of Indigenous data sovereignty and governance into its research programs.

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## Highlights

- There is a demonstrated need to change current Indigenous research data collection practices in favour of an approach that embraces Indigenous world views and puts Indigenous peoples in control of their data.
- Indigenous data need to be accessed and linked in ways that are determined by Indigenous governance groups, thereby facilitating culturally appropriate answers to questions that were previously taken from Indigenous peoples.

## Background

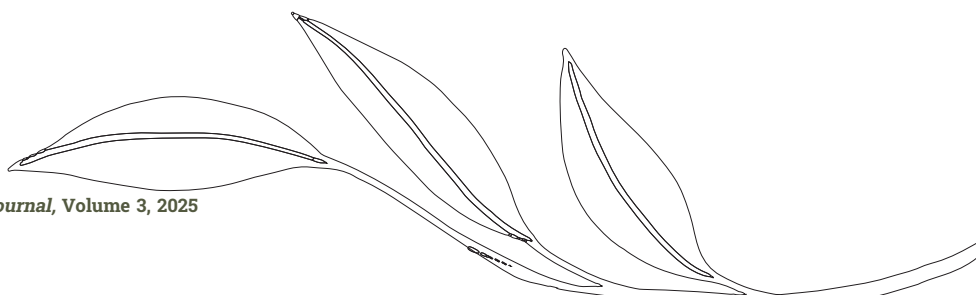
The current health and social inequities experienced by Indigenous peoples in Australia and globally confirm that ‘historical colonisation and contemporary settler-colonialism have created systems, structures and processes that marginalise, discriminate and oppress Indigenous peoples’ (Williamson and Price 2023, p. 282). These systems and structures permeate all facets of Indigenous lives, including research institutions and governance practices and processes related to collection, analysis, use and dissemination of Indigenous data. At the heart of these systems and structures are data that position non-Indigenous values, knowledge and lived experiences as the norm, and Indigenous values, knowledge and lived experiences as divergent and lesser. These have been characterised by Walter and colleagues as BADDR data:

- **Blaming data**, which rate Indigenous peoples poorly against the non-Indigenous norm.
- **Aggregate data** at a national and/or state level, which implies Indigenous cultural and geographical homogeneity.
- **Decontextualised data** that are simplistic and decontextualised, focusing on individuals and families outside of their social/cultural context.
- **Deficit, government priority data**, which focuses on disadvantage, disparity, dysfunction, difference and deficit.

- **Restricted access data** that are inaccessible to Indigenous peoples and communities (Walter et al. 2021).

This pervasive bias has informed the development of policies and practices in relation to Indigenous peoples, with the result that solutions to perceived and actual problems were almost always doomed to fail with inherent risks to a range of wellbeing factors and self-determination (Walter et al. 2021). However, increased interest in the rights, knowledges and identities of Indigenous peoples, culminating in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) in 2007, ‘has led to the emergence of Indigenous data sovereignty, an assertion of the rights and interests of Indigenous peoples in relation to data about them, their territories, and their ways of life’ (Carroll et al. 2020, p. 3).

Governments, health and research institutions are now being urged (Closing the Gap 2020) to change current data collection practices in favour of approaches that embrace Indigenous world views and put Indigenous peoples in control of their data. This is recognised in the Closing the Gap report (Closing the Gap 2020), where a priority recommendation calls for enhanced formal governance partnerships between Aboriginal and Torres Strait Islander peoples and all Australian governments to facilitate shared





decision-making for health policies, with a particular emphasis on social and emotional wellbeing. This has strong potential to augment existing strengths and empowerment of Aboriginal and Torres Strait Islander communities and peoples.

Research institutions and sponsors are also urged to incorporate Indigenous data sovereignty approaches into relevant features of research infrastructure, such as project applications, contracting, ethics review, researcher training, metadata fields, data management and repository policies, funding requirements, and community engagement, thereby restoring respectful, equitable relationships with Indigenous peoples after centuries of unequal and exploitative engagements. Importantly, these self-determining processes acknowledge Indigenous peoples' rights and cognisance of research and data, in addition to generating data governance systems, signifying that these critical elements have historically been limited by historical and ongoing colonial law and policies (Garba et al. 2023).

### International developments in Indigenous data sovereignty

Writing about the development of Indigenous data sovereignty in the United States, Rodriguez-Lonebear observed that 'the word data comes from the Latin *datum*, meaning something given. However, Indigenous experiences under colonial control suggest that data more often means something taken' (Rodriguez-Lonebear, 2016, p. 255). However, the beginnings of assertion of sovereignty over Indigenous data came when data was not taken. In 1994, the Canadian Government conducted three major population surveys but excluded First Nations people living on reserves from the surveys. In response, the Assembly of First Nations formed a National Steering Committee, in 1996, to design a new First Nations

health survey and shortly after developed the First Nations Principles of OCAP – ownership, control, access and possession – to acknowledge the importance of First Nations peoples possessing their own data. In 2000, the National Steering Committee was repositioned as the First Nations Information Governance Committee and began data collection for a First Nations Regional Longitudinal Health Survey in 2002 (First Nations Governance Centre 2024).

The OCAP principles are broadly defined and allow for contextual interpretation:

- Ownership refers to the relationship between a community and their data; specifically, First Nations own information about themselves in a manner akin to how individuals own information about themselves. This right to ownership applies regardless of where data are stored.
- Control refers to the right of First Nations to govern how information about them is collected, used and disclosed.
- Access refers to the right of First Nations to access their data, including the results of analyses conducted using their data, as well as to determine who else can access their data.
- Possession refers to the right of First Nations to govern how their data are stored, including the appointment of data stewards (Indigenous Primary Health Care Council 2023).
- Possession has also been described as having physical control of data and a mechanism by which First Nations peoples and communities can protect their data, including privacy provisions (First Nations Information Governance Centre 2024).

However, it is important to note that OCAP is not universally applied across Canada and has continued to evolve over the last 30 years; individual Indigenous





nations within Canada have identified their own sets of core principles. Working with the Institute for Clinical Evaluation Sciences, for example, the Chiefs of Ontario created a set of four principles for data governance:

- Ethical relationships
- Formalised data governance rules
- Using evidence to support community policies and programs
- Embracing Indigenous perspectives and worldviews (IPHCC 2023).

The UNDRIP declaration referred to above contains 40 articles on the rights of Indigenous peoples, three of which are particularly relevant here:

#### Article 3

Indigenous peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.

#### Article 23

Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, Indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions.

#### Article 31

Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies

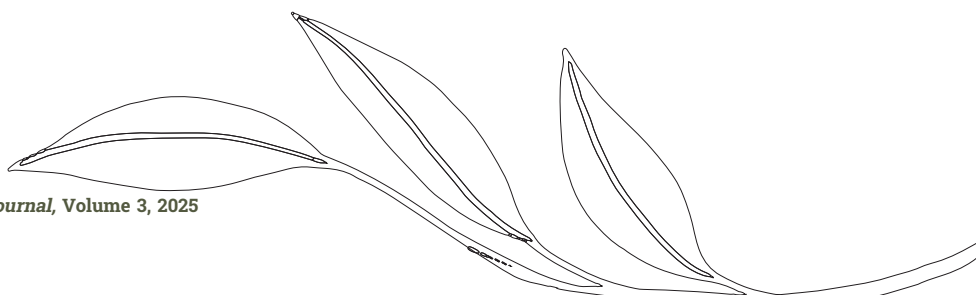
and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions (United Nations 2025).

Although rights pertaining to data are not explicitly mentioned in the Declaration (Davis 2016), the United Nations Permanent Forum on Indigenous Issues recognised that the lack of disaggregated data was inhibiting governments and intergovernmental bodies in formulating and implementing Indigenous-sensitive decisions and programs. The UN Special Rapporteur on the Rights of Indigenous Peoples noted that Indigenous peoples:

*... should control these data and that their effective participation in data gathering and research should be ensured. Furthermore, resulting data should be available for use by them in policy articulation, in planning and in monitoring and evaluation efforts (Tauli-Corpuz 2019, p. xxi-xxiii).*

Additionally, it has been noted that the concept of data sovereignty is linked to Articles 3 and 31, which highlight Indigenous peoples' rights to self-determination and to control manifestations of their sciences, technologies and cultures, including human and genetic resources (United Nations 2025). Self-determination in relation to data sovereignty includes the collection and management of information that reflects the Indigenous laws, practices and customs of the associated nation-state (Snip 2016).

Since the 2007 UN adoption of UNDRIP, academics, researchers and practitioners around the world have been exploring the concepts of Indigenous data





sovereignty and Indigenous data governance, often with international collaboration in writing articles and organising conferences.

In New Zealand, the Te Mana Raraunga (Māori Data Sovereignty Network) was established in 2015 to consider and manage the implications of the UNDRIP on ownership of data relating to Māori peoples, researchers and practitioners (Te Mana Raraunga - Māori Data Sovereignty Network Charter, n.d.). In 2023 a Māori Data Governance Model was developed by Māori experts for use across the New Zealand public service, noting the urgent need for related monitoring, compliance and evaluation to assess effectiveness and support gaps (Kukutai et al. 2023).

In 2017 the International Indigenous Data Sovereignty Interest Group was established and in 2019 a workshop held in Spain to examine data infrastructures included participants from Australia, New Zealand and the United States. This workshop led to the formation of the Global Indigenous Data Alliance, which developed the CARE principles for Indigenous Data Governance (GIDA 2024). In 2023, the Global Indigenous Data Alliance published a set of Indigenous peoples' rights in data (Table 1), distinguishing between data for governance (the ability for Indigenous communities to

access and use data themselves) and governance of data (the ability of Indigenous communities to internally steward and externally influence the use of data) (Hudson et al. 2023):

The first United States Summit for Indigenous data sovereignty was held in 2019 at Arizona State University, with the inaugural National Conference held in April 2024 (Baker 2024). The United States Indigenous Data Sovereignty Network endorsed the following data governance principles:

- Collective wellbeing, past and future oriented, across generations, equitable outcomes
- Protection, ethics, responsibility, equal explanatory power, equitable outcomes
- Inherent sovereignty, self-determination, control, access
- Relationships, responsibility, reciprocity, between nations and governments
- Indigenous knowledge (honouring), reflexive of the people, relationship to the non-human world (Rainie et al. 2017).

Collaborations between New Zealand and Australian researchers, particularly with the establishment of the International Indigenous Data Sovereignty Interest

| Data for governance  | Governance of data   |
|--|--|
| <i>Right to self-determination</i> the ability to organise and control data in relation to a collective identity   | <i>Right to govern</i> the right to lead and collaborate in the development and implementation of protocols and in decisions about access to data                        |
| <i>Right to reclaim</i> the right to reclaim, retain and preserve data, data labels and data outputs that reflect Indigenous peoples' identities, cultures and relationships | <i>Right to define</i> the right to define lifeways of knowing and being including how they are represented in data  |
| <i>Right to possess</i> the ability to exercise jurisdictional control over the ways that data flow/move/are queried   | <i>Right to privacy</i> the protection of collective identities and interests from undue attention, also including the possibility of requesting omission and/or erasure |
| <i>Right to use</i> the ability of individuals and collectives to use data for their own purposes  | <i>Right to know</i> the ability to track the storage, use, and reuse of the data and who has had access to them   |
| <i>Right to consent</i> the expression of digital autonomy and the ability to assess risks and accept potential harms  | <i>Right to association</i> the recognition of provenance and terms of attribution   |
| <i>Right to refuse</i> the right to say 'no' to certain uses of data   | <i>Right to benefit</i> the opportunity to benefit from the use of data and equitable benefit sharing from derivatives of data   |

**Table 1: Indigenous peoples' rights in data and governance of data (Global Indigenous Data Alliance 2024; Hudson et al. 2023)**





Group in 2017 and the group's 2019 workshop in Spain, assisted in developments in the Australian context.

## The Australian context

The Australian Government endorsed the UN Declaration in 2009 and identified the Closing the Gap Strategy as its key policy platform to give effect to the Declaration. However, it took a further 10 years before the 2019 National Partnership Agreement on Closing the Gap saw the involvement of the Coalition of Aboriginal and Torres Strait Islander Peak Bodies as partners and decision-makers (Abstarr 2023).

The concept of Indigenous data sovereignty was addressed at a workshop on data sovereignty for Indigenous peoples in July 2015 (Kukutai and Taylor 2017). Several years later, the Maiam nayri Wingara Indigenous Data Sovereignty Collective was formed to develop Aboriginal and Torres Strait Islander data sovereignty principles and to identify Aboriginal and Torres Strait Islander strategic data assets (Maiam nayri Wingara 2024). In 2018, delegates who had attended an Indigenous data sovereignty summit endorsed the following foundational statements:

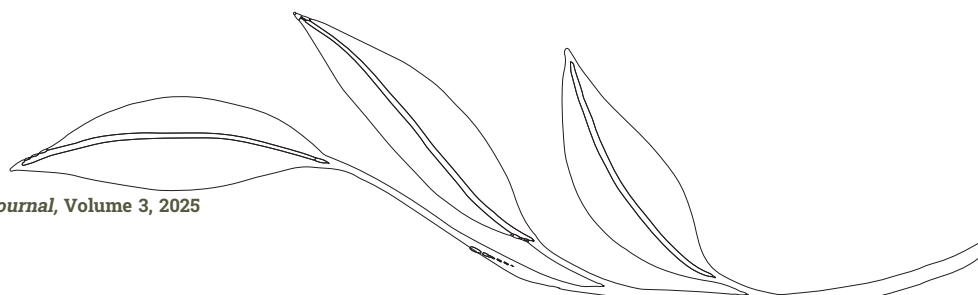
- 'Indigenous data' refers to information or knowledge, in any format or medium, which is about and may affect Indigenous peoples both collectively and individually.
- 'Indigenous data sovereignty' refers to the right of Indigenous peoples to exercise ownership over Indigenous data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination and reuse of Indigenous data.
- 'Indigenous data governance' 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 our priorities, values, cultures, worldviews and diversity (Maiam nayri Wingara 2018).

A second summit was held in 2023 in Cairns. Over 130 Indigenous delegates from across Australia attended, along with international experts from Aotearoa (New Zealand), Canada and the United States (Maiam nayri Wingara 2023). The delegates asserted that the realisation of Indigenous data governance:

- Adheres to the internationally agreed definitions of Indigenous data sovereignty and Indigenous data governance, as per the 2018 summit
- Must be integrated at all data lifecycle stages, utilising mechanisms aligned with Indigenous determined needs and aspirations
- Requires Indigenous leadership and control over all Indigenous data governance processes
- Requires widespread Indigenous data literacy and capability by allocating resources for Indigenous workforce expansion and investing in digital infrastructure and systems aligned with Indigenous priorities
- Is based on ensuring accountability of entities that hold Indigenous data, ensuring that data are available to and accessible by the Indigenous peoples and lands to which they relate
- Requires that the creation of new data incorporate Indigenous data governance mechanisms, guaranteeing that data production is ethical, representative and beneficial.

Indigenous communities maintain the right to decide which datasets require active governance and retain the right to abstain from participating in data processes inconsistent with the principles stated in this communique.





Implementing Indigenous data governance requires moving well beyond participation, dissemination and translation. Indigenous data governance requires equipping Indigenous leaders, practitioners and community members with the necessary support, skills and infrastructure to advocate and participate across all data aligned sectors and jurisdictions ([Maiam nayri Wingara, Australian Indigenous Governance Institute and Lowitja Institute 2023](#)).

The Indigenous Data Network (IDN) has subsequently embarked on a long-term project to develop these necessary skills and infrastructure. The IDN was established in 2018 to support and coordinate the governance of Indigenous data for Aboriginal and Torres Strait Islander peoples and empower Aboriginal and Torres Strait Islander communities to decide their own local data priorities. The IDN is a national network of Aboriginal community-controlled organisations, university research partners, Indigenous businesses and government agencies and departments. It is led by a steering committee of experts and stakeholders and the founding partnership between the University of Melbourne, the Australian National University and the Australian Institute for Aboriginal and Torres Strait Islander Studies (AIATSIS) ([Melbourne School of Population and Global Health 2024](#)) The IDN was established to:

- empower Aboriginal and Torres Strait Islander communities to decide their own local data priorities, including how their data are used
- ensure those decisions are supported and reinforced by national legal and policy frameworks, as well as the FAIR and CARE data principles (see below) and principles of Indigenous data democracy, stewardship, analysis, dissemination and infrastructure (Australian Research Data Commons 2024).

The Australian Research Data Commons (ARDC) is a facility for research data infrastructure providing strategies supporting Australian researchers ([ARDC 2025a](#)). A collaborative project between the IDN and the ARDC is working to improve research proficiency through three streams of development activities within the Australian Indigenous Research Capability program, with the aim of designing a specific Aboriginal and Torres Strait Islander Research Data Commons through:

- social architecture: empowering Indigenous data governance and sovereignty
- technical architecture: building the foundations for an Aboriginal and Torres Strait Islander Research Data Commons
- core national Indigenous data assets: building an Aboriginal and Torres Strait Islander spatiotemporal framework ([ARDC 2024a](#)).

The core objectives guiding these improvements are to:

- collectively agree on, and apply, a set of uniquely Australian, Aboriginal and Torres Strait Islander data governance principles
- enable Aboriginal and Torres Strait Islander organisations and researchers to sustainably manage their data
- establish the breadth and depth of Aboriginal and Torres Strait Islander research data available across Australia that are relevant to the needs of Aboriginal and Torres Strait Islander peoples
- develop the foundations of an Aboriginal and Torres Strait Islander Data Commons
- value adding through access to appropriate aggregation and analysis tools ([Indigenous Data Network 2022](#)).

Two foundational outcomes to date have seen the development of Indigenous sovereign data





capabilities, tools and infrastructure and the creation of novel culturally appropriate data governance frameworks that align with community needs (ARC 2025).

## Frameworks

In the years since UNDRIP, researchers and academics, both nationally and internationally, have developed a range of frameworks and models to implement Indigenous data governance and give effect to Indigenous data sovereignty. This section provides an overview of the frameworks and models that are most relevant to and inform/underpin the research and advocacy principles and practice of the Ngangk Yira Institute for Change.

## FAIR principles

The Findable, Accessible, Interoperable and Reusable (FAIR) principles were developed for the use of scientific data in 2018, with the objective being to maximise the benefits gained from data assets through making them findable, accessible, interoperable and reusable. The emphasis is on easily attracting meaningful metadata, thereby maximising potential of data assets and the ability to compare outcomes internationally, in addition to enhancing research reproducibility and dependability (ARDC 2024b; Carroll et al. 2021).

### Findable

The data have sufficiently rich metadata and a unique and persistent identifier to be easily discovered by others. This includes assigning a persistent identifier (like a Digital Object Identifier or Handle), having rich metadata to describe the data and making sure it is findable through disciplinary local or international discovery portals.

### Accessible

The data are retrievable by humans and machines through a standardised communication protocol, with authentication and authorisation where necessary. The data do not necessarily have to be open. Data can be sensitive due to privacy concerns, national security or commercial interests. When it is unable to be open, there should be clarity and transparency around the conditions governing access and reuse.

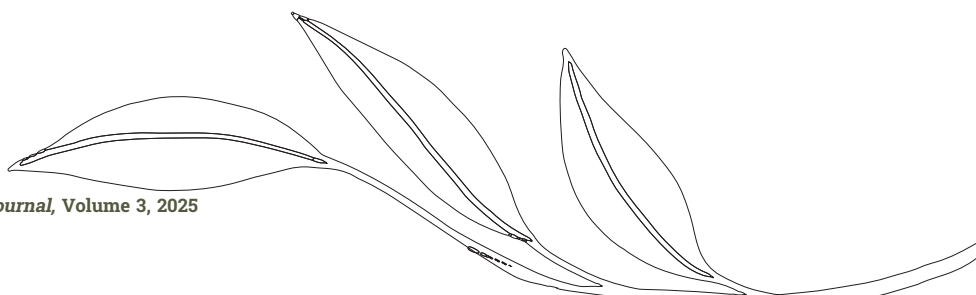
### Interoperable

The associated data and metadata use a 'formal, accessible, shared, and broadly applicable language for knowledge representation'. This involves using community accepted languages, formats and vocabularies in the data and metadata. Metadata should reference and describe relationships to other data, metadata and information through identifiers.

### Reusable

The associated metadata provide rich and accurate information, and the data come with a clear usage licence and detailed provenance information. Reusable data should maintain their initial richness. For example, they should not be diminished for the purpose of explaining the findings in one particular publication. They need a clear machine-readable licence and provenance information on how the data were formed. They should also use discipline-specific data and metadata standards to give rich contextual information that will allow reuse (ARDC 2024b).

Data involving Indigenous peoples that have been generated through FAIR principles have a complexity of ethical considerations needing to be addressed. As such, CARE principles also need to be applied to the data (ARDC 2024b).





## CARE principles

The 'CARE principles for Indigenous Data Governance' were formulated by the Global Indigenous Data Alliance (GIDA) in 2018 to address deficits regarding Indigenous peoples' rights and interests in the existing FAIR principles (ARDC 2024b). The rationale behind the development of the CARE principles reflects the observation that mainstream Western research and data values often do not align with Indigenous cultures and collective rights. Indigenous governance processes and world views have focused on 'people' and 'purpose', which highlight collective ownership and control of data. The CARE principles for Indigenous data governance offer an empowering approach for Indigenous peoples through value-based relationships that centre data collection and reuse within their cultures and knowledge systems, thereby offering more equitable outcomes (Carroll et al. 2019).

The CARE principles acknowledge the critical role that data play in advancing the enactment of Indigenous self-determination. These address concerns related to the people and purpose of data and are premised on the belief that the use of Indigenous data should result in tangible benefits for Indigenous collectives through inclusive development and innovation, improved governance and citizen engagement, and equitable outcomes. The CARE principles encompass collective benefit, authority to control, responsibility and ethics.

### Collective benefit

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

- Governments and institutions must actively support the use and reuse of data by Indigenous nations and

communities by facilitating the establishment of the foundations for Indigenous innovation, value generation and the promotion of local self-determined development processes.

- Data enrich the planning, implementation and evaluation processes that support the service and policy needs of Indigenous communities. Data also enable better engagement between citizens, institutions and governments to improve decision-making. Ethical use of open data has the capacity to improve transparency and decision-making by providing Indigenous nations and communities with a better understanding of their peoples, territories and resources. It similarly can provide greater insight into third-party policies and programs affecting Indigenous peoples.
- Indigenous data are grounded in community values, which extend to society at large. Any value created from Indigenous data should benefit Indigenous communities in an equitable manner and contribute to achieving Indigenous needs and aspirations for wellbeing.

### Authority to control

Indigenous peoples' rights and interests in Indigenous data must be recognised and their authority to control such data be acknowledged and empowered. Indigenous data governance enables Indigenous peoples and governing bodies to determine how Indigenous peoples – as well as Indigenous lands, territories, resources, knowledges and geographical indicators – are represented and identified within data as well as ensuring the following rights.

- Indigenous peoples have rights and interests in both Indigenous knowledge and Indigenous data. Indigenous peoples have collective and individual rights to free, prior and informed consent in the





collection and use of such data, including the development of data policies and protocols for collection.

- Indigenous peoples have the right to data that are relevant to their world views and empower self-determination and effective self-governance. Indigenous data must be made available and accessible to Indigenous nations and communities to support Indigenous governance.
- Indigenous peoples have the right to develop cultural governance protocols for Indigenous data and be active leaders in the stewardship of, and access to, Indigenous data, especially in the context of Indigenous knowledge.

## 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. Accountability requires meaningful and openly available evidence of these efforts and the benefits accruing to Indigenous peoples.

- Indigenous data use is unviable unless linked to relationships built on respect, reciprocity, trust and mutual understanding, as defined by the Indigenous peoples to whom those data relate. Those working with Indigenous data are responsible for ensuring that the creation, interpretation and use of those data uphold, or are respectful of, the dignity of Indigenous nations and communities.
- Use of Indigenous data invokes a reciprocal responsibility to enhance data literacy within Indigenous communities and to support the development of an Indigenous data workforce and digital infrastructure to enable the creation, collection, management, security, governance and application of data.

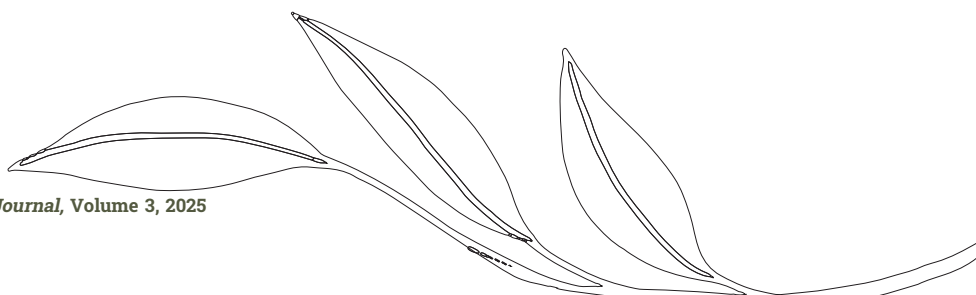
- Resources must be provided to generate data grounded in the languages, worldviews and lived experiences (including values and principles) of Indigenous peoples.

## Ethics

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

- Ethical data are data that do not stigmatise or portray Indigenous peoples, cultures or knowledges in terms of deficit. Ethical data are collected and used in ways that align with Indigenous ethical frameworks and with rights affirmed in UNDRIP. Assessing ethical benefits and harms should be performed from the perspective of the Indigenous peoples, nations or communities to whom the data relate.
- Ethical processes address imbalances in power, resources and how these affect the expression of Indigenous rights and human rights. Ethical processes must include representation from relevant Indigenous communities.
- Data governance should consider the potential future use and future harm based on ethical frameworks grounded in the values and principles of the relevant Indigenous community. Metadata should acknowledge the provenance and purpose and any limitations or obligations in secondary use inclusive of issues of consent ([Research Data Alliance International Indigenous Data Sovereignty Interest Group 2019](#)).

The AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research states that 'researchers must be aware of and apply the international data principles of FAIR ([ARDC 2024b](#)) (see below) and CARE' ([Australian Institute of Aboriginal and Torres Strait Islander Studies 2020](#)). The four principles that





structure the AIATSIS research ethics framework (left column) align with the CARE principles (right column):

|                                   |                      |
|-----------------------------------|----------------------|
| Indigenous self-determination     | Collective benefit   |
| Indigenous leadership             | Authority to control |
| Impact and value                  | Responsibility       |
| Sustainability and accountability | Ethics               |

The CARE principles are reflected in the five values ([Research Data Alliance International Indigenous Data Sovereignty Interest Group 2019](#)) that provide the basis for the National Health and Medical Research Council (NHMRC) guidelines for Ethical conduct in research with Aboriginal and Torres Strait Islander peoples and communities. Although there is not a one-to-one relationship, each of the CARE principles can be aligned with one or more of the core values of:

- Cultural continuity
- Equity
- Reciprocity
- Respect
- Responsibility.

The CARE principles also mirror the five key principles that underpin the Lowitja Institute's approach to research:

- Beneficence – to act for the benefit of Aboriginal and Torres Strait Islander peoples in the conduct of our research
- Leadership by Aboriginal and Torres Strait Islander peoples
- Engagement of research end users (Aboriginal and Torres Strait Islander organisations and communities, policymakers, other potential research users)
- Development of the Aboriginal and Torres Strait Islander research workforce

- Measurement of impact in improving Aboriginal and Torres Strait Islander peoples' health ([Lowitja Institute 2024](#)).

The CARE and FAIR principles informed the Framework for Governance of Indigenous Data developed for use in the Australian Public Service ([Commonwealth of Australia 2024](#)) (see below).

The CARE principles are designed to complement the FAIR principles and other mainstream data frameworks, and promote equitable participation and outcomes from data access, use, reuse and attribution in contemporary data landscapes. However, there may be tension between the openness of the FAIR principles and the need to protect Indigenous rights and interests in data ([Carroll et al. 2021](#)). To the extent that the CARE and FAIR principles may conflict in the context of Indigenous research, the CARE principles should prevail.

### Indigenous genomics

Indigenous data sovereignty is particularly important and more difficult to implement in the data science within Indigenous genomics. Innovative partnership models of research governance are needed across Australian and international interdisciplinary health and research jurisdictions for this emerging area of cultural and scientific significance to Indigenous data sovereignty. The Australian National Centre for Indigenous Genomics ([NCIG 2020](#)) has a governance framework to ensure that genomic data are under Indigenous custodianship, in addition to appropriate engagement with Indigenous peoples from whom data are collected. The Native BioData Consortium in the United States ([NBDC 2021](#)) advocate for Indigenous genomic data sovereignty in relation to Indigenous





peoples' ownership, benefit and self-governance of their genetic information. Both centres highlight the ongoing innovation within this vital health and research area, with the critical need for rigorous Indigenous data sovereignty models of oversight.

## The InDatOCS model

The Indigenous Data Ownership, Custodianship and Stewardship (InDatOCS) model was developed by the Indigenous Data Network based at the University of Melbourne. (Rose et al 2023) The framework stems from a broader partnership with the National Indigenous Australians Agency to examine the ways that Indigenous community organisations collect, store and use data, and how that data can be enhanced to further empower the work they do.

Many Indigenous community organisations already collect data that are based on Indigenous-designed data, information and knowledge structures consistent with Indigenous community priorities. These data assets can become more valuable when linked with government data to highlight gaps and alignments. It is intended that this linking process be regulated by a comprehensive Indigenous-led data governance framework (Rose 2021).

In developing this framework Rose and colleagues (2023) reviewed a range of internationally accepted

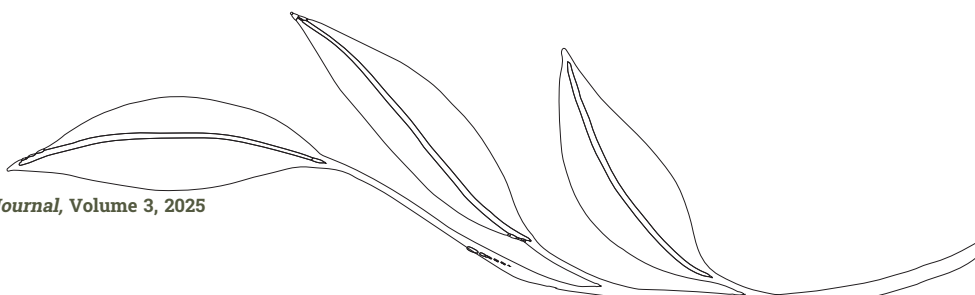
models for data management and synthesised those features most applicable to Indigenous data governance. They defined data governance as 'an organisational system comprised of roles and relations, each of which are defined by intersecting functions'. (Rose et al 2023 p. 4) The roles, functions and relations of an OCS data governance model are summarised in Table 2 and Figure 1.

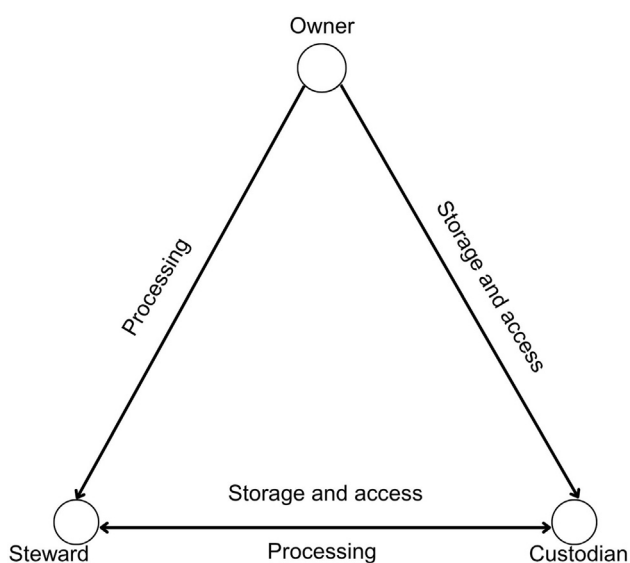
This model of data governance, the authors noted:

*introduces an important perspective for the governance of Indigenous data where, under most current legal frameworks, government performs all three roles of owner, custodian, and steward. This is the case even where the legislation under which data may originally have been generated has since been repealed, including various state and territory Aboriginal 'Protection' acts and the sections of Australia's federal constitution that devolved all powers regarding Indigenous Peoples to state and territory governments prior to 1967. ... [T]he general administrative assumption in Australia has been that data generated by and about Indigenous individuals and communities under moribund legislation, automatically takes on the form of 'archival records,' the most relevant governing instruments for which are contained in privacy legislation (Rose et al. 2023, pp. 5-6).*

|                       |   |
|-----------------------|---|
| <b>Data Owner</b>     | <b>Function:</b> Determines all purposes for which and means by which data assets are generated, stored, accessed, processed and destroyed.<br><b>Relation 1:</b> data owner->data custodian (determines custodianship)<br><b>Relation 2:</b> data owner->data steward (determines stewardship)   |
| <b>Data Custodian</b> | <b>Function:</b> supplies data storage and access services.<br><b>Relation 1:</b> data custodian<-data owner (supplies custodianship services on behalf of data owner)<br><b>Relation 2:</b> data custodian<->data steward (supplies access and storage services to data steward)   |
| <b>Data Steward</b>   | <b>Function:</b> supplies data processing services, including creation, linkage, modelling, analysis and destruction.<br><b>Relation 1:</b> data steward<-data owner (supplies stewardship services on behalf of data owner)<br><b>Relation 2:</b> data steward->data custodian (supplies processing services to a data custodian) (Rose et al. 2023) |

**Table 2: Roles, functions and relations of an Owner Custodian Steward (OCS) data governance model (Jones et al. 2023 p. 4)**





**Figure 1:** Visualisation of the (O)wnership, (C)ustodianship and (S)tewardship (OCS) model of data governance, integrating the roles, functions and relations of systematic data (Rose et al. 2023, p. 5).

Rose and colleagues (2023) described Indigenous data as a special spatiotemporal class of personal data, noting that the existence of Indigenous peoples and communities in the present implies an unbroken process of population regeneration before others arrived here, thus giving Indigenous data a unique characteristic. Their data relating to land, ownership and management of natural resources, labour and intellectual property have been recognised as historical and ongoing tangible assets that are very distinct from those of non-Indigenous peoples.

They also examined a range of non-enforceable international guidelines and principles, including the Five Safes framework; the FAIR guiding principles; the CARE principles; OCAP; and the ALCOA Data Integrity Principles and TRUST principles.

The Five Safes framework was originally developed in 2003 by the United Kingdom's Office of National

Statistics as a set of protocols for managing conditions on data access and is most closely focused on the role and functions of data custodianship (Desai et al. 2016; Ritchie 2017). In Australia, all Commonwealth accredited integrating authorities conform to the framework, including the Australian Bureau of Statistics, the Australian Institute of Health and Welfare (AIHW), the Australian Institute of Family Studies, and the Commonwealth Department of Social Services, among others (Rose et al. 2023 p. 14; Desai et al. 2016; Ritchie 2017). The Five Safes, as originally developed, refer to Safe projects, Safe people, Safe data, Safe settings and Safe output. Rose and colleagues (2023) refined the framework to make it functionally more useful as a national framework for Indigenous data governance, as noted in Table 3.

The effectiveness of the Five Safes framework is dependent on the inclusion of comprehensive risk assessments and security controls. However, the application of these principles preserves individual privacy while enhancing partnerships between data custodians and researchers (Ward 2024).

The Attributable, Legible, Contemporaneous, Original and Accurate (ALCOA) principles were originally developed as a mechanism for regulating data relating to pharmaceutical products (and later, medical equipment) in the United States (Rose 2023; McDowall 2018; Williams et al. 2017; Woollen 2010). The principles were later expanded to include medical equipment, with the added principles of Complete, Consistent, Enduring, and Available with the acronym being modified to ALCOA+ (Jordan 2016).

In 2019, the World Health Organization adopted these principles and acknowledged that these are more broadly applicable to the maintenance of data integrity



|               |  |
|---------------|--|
| Safe projects | Is the proposed custodianship and stewardship of the data in the interests of Indigenous data owners?  |
| Safe people   | Do data custodians and stewards have the experience, knowledge, skills and motivation to act in the interests of Indigenous data owners?       |
| Safe data     | Have the data been assessed to measure their potential for undermining the interests of their Indigenous owners?                               |
| Safe settings | Have custodianship and stewardship functions been set to minimise risks of the data being used contrary to the interests of Indigenous owners? |
| Safe output   | Are the results of modelling and analysing Indigenous data non-disclosive? (Rose et al 2023, p. 17)  |

**Table 3: National framework for Indigenous data governance (Rose et al. 2023 p. 14)**

throughout data lifecycles (WHO 2019; Rose et al. 2023). The temporal aspect is relevant, as:

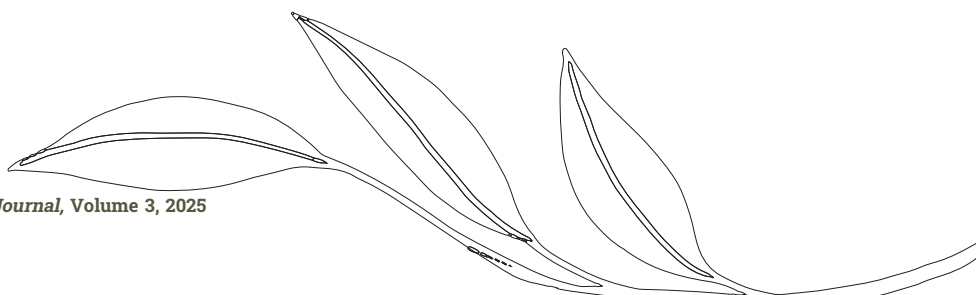
*those data assets currently treated as Indigenous ‘archival records,’ are more properly treated as Indigenous ‘data products,’ which exhibit supply chain histories comparable to life science data and medical products typically subject to the WHO’s ALCOA+ guidelines (Rose et al. 2023, pp. 17–18).*

The (T)ransparency, (U)ser-focus, (S)ustainability, and (T)echnology (TRUST) principles for digital repositories were, like the CARE principles described above, developed in response to the FAIR principles, also described above, thereby reflecting the crucial role of data in self-determination (Commonwealth of Australia 2024). The TRUST principles aim for more ethical obligations toward data owners on the part of the data stewards and data controllers and, as Rose and colleagues note, ‘may assist in giving rise to a more just outcome’ (Rose et al. 2023, p. 22).

Following their review of existing data governance frameworks, legislation, guidelines and principles, Rose and colleagues (2023, p. 23) identified six key features that can be integrated into an Indigenous data governance framework based on the following definitions:

1. The definition of the relationship between data sovereignty and data governance, where:

- a. Data sovereignty refers both to the aspiration of Indigenous individuals and communities to autonomous ownership and control of data assets in which they hold an interest, and to the legally enforceable mandate of governments to exert authority over the governance of data within a given jurisdictional domain, and where;
  - b. Data governance refers to the roles, functions and relations involved in exerting this authority, which consequently encompass the concept of sovereignty.
2. The definition of data as the semantic product of cognitive and intellectual work in a sequential process undertaken over time, which follows the preceding generation of at least two other semantic products, including knowledge and information, such that the production chain involved in the generation of data follows the sequence knowledge>information>data.
  3. The definition of data as an intangible asset with real financial value.
  4. The definition of data governance as an organisational system titled ‘OCS’, comprised of roles, functions and relations, namely:
    - a. Three roles: ownership, custodianship and stewardship
    - b. Two sets of functions: controlling and processing
    - c. Three relations: owner<>custodian; custodian:<>steward; steward<>owner.
  5. The definition of a data life cycle as encompassing all instances of controlling and processing





between the instant of a dataset's creation and the instant of its destruction over time.

6. The definition of Indigenous data as a special class of data asset distinguished by its multi-generational life cycle, extending over a period that predates the assertion of a colonial data governance regime (Rose et al. 2023, pp. 22-23).

Rose et al. (2023) have proposed that these six key features of current data governance frameworks and principles are integrated into a specific Indigenous self-determining governance framework across all Australian states, also recognising data governance roles of ownership, stewardship and custodianship.

### A data ecosystem approach

Walter and Suina (2019) reflected on their experiences as Indigenous scholars and their awareness of a lack of fit between Western methodology and Indigenous research. They described an Indigenous methodology as one which puts Indigenous worldviews, perspectives, values and lived experience as its central axis (Walter and Suina 2019, p. 234). This is contrasted with a Western positivist approach that appears objective but is in fact predicated on notions of difference between the 'problematic Indigene' and the non-Indigenous norm, resulting in what Walter and Suina (2019, p. 236) described as 5D data: difference, disparity, disadvantage, dysfunction and deprivation. Walter and Suina see a need for specific Indigenous data protocols through which Indigenous data sovereignty can be exercised:

*Data sovereignty is practiced through Indigenous data governance, which assert Indigenous interests in relation to data. The primary vehicle is Indigenous decision-making across the data ecosystem: from data conception to control of access to and usage of data. Indigenous decision-making is a prerequisite for*

*ensuring Indigenous data reflects Indigenous priorities, values, culture, lifeworlds and diversity (2019, p. 237).*

The data ecosystem approach has been adopted in the Framework for Governance of Indigenous Data: Practical guidance for the Australian Public Service (Commonwealth of Australia 2024) developed by the Commonwealth Government with input from the Data Champions Network (Commonwealth of Australia 2024, p. 23). The Framework, although comprehensive, does not privilege Indigenous decision-making across the entire data ecosystem as Walter and Suina envisioned. Rather, the Framework is intended to guide government agencies in Australia on the pragmatics of implementation and embedding the areas of data governance where the objectives of the Indigenous data sovereignty movement and the Australian Government align (Commonwealth of Australia 2024, p. 8).

This Framework is structured around the different stages of the data lifecycle.

### System design and technology

- The data lifecycle of First Nations data should be underpinned by a system that is co-created by Aboriginal and Torres Strait Islander peoples to reflect needs and priorities.
- Systems design of data storage should be grounded in Aboriginal and Torres Strait Islander design and stewardship of data, including appropriate identifiers.
- System design should articulate a clear model of governance that is rooted in Indigenous governance.
- The data system design should facilitate data linkage that meets the information needs of communities.

### Conceptualisation and creation

- Aboriginal and Torres Strait Islander peoples, including from communities about which the data relate, as appropriate, should have significant input in the conceptualisation and creation of Indigenous data.





- Is government asking the right questions to respond to Aboriginal and Torres Strait Islander communities' priorities and aspirations? Where possible, data should be viewed as a commons that groups exercise a collective right to shape and access.
- Indigenous data should be subject to change when Aboriginal and Torres Strait Islander peoples request.
- Data should be created to support Indigenous data needs and empower sustainable self-determination and effective self-governance.
- Data should be conceptualised to reflect the Indigenous lifeworld.
- Data are contextualised so that they are strengths-based rather than deficit-focused where possible.

## Collection

- Indigenous data should always be collected ethically and respectfully.
- Free, prior and informed consent should be obtained in culturally safe and appropriate ways, clearly articulating benefits and risks.
- Collection practices should be grounded in ethical standards that are grounded in Aboriginal and Torres Strait Islander peoples' priorities.
- Community surveys should be able to temporarily or on an ongoing basis be suspended at the discretion of Aboriginal and Torres Strait Islander peoples to align with community practices and needs (including Sorry Business, etc.).
- Metadata from the collection should include contextual information, including the provenance of Indigenous data.

## Access

- Aboriginal and Torres Strait Islander peoples need access to their data.
- Support should be provided to Aboriginal and Torres Strait Islander communities, where necessary, to

access the required IT capacity and infrastructure for community data access.

- Aboriginal and Torres Strait Islander peoples need access to their data in useable forms.
- Aboriginal and Torres Strait Islander communities should be supported by the government, where appropriate, to manage and maintain their own data resources.

## Analysis

- Aboriginal and Torres Strait Islander peoples need to be involved in analysis to provide context and build capability to analyse data.
- Aboriginal and Torres Strait Islander perspectives should shape not only the choice of methods, but how the data are analysed.
- Methodology for analysis should be designed in collaboration with Aboriginal and Torres Strait Islander peoples.

## Interpretation

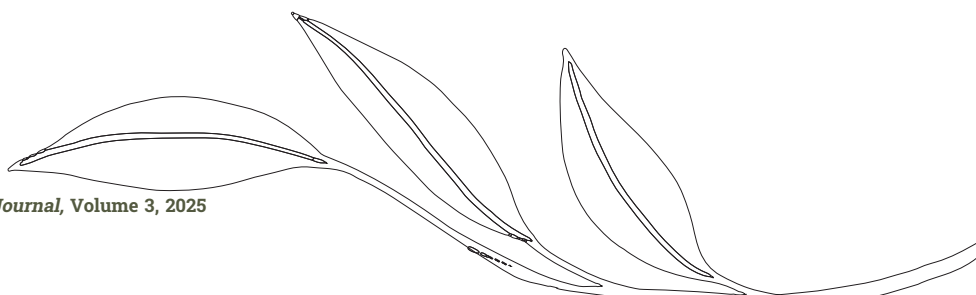
- Anyone interpreting Indigenous data needs to understand Aboriginal and Torres Strait Islander perspectives and the complexities of colonisation.
- Aboriginal and Torres Strait Islander peoples should have the right to self-determination over their data-driven narrative.
- Indigenous data interpretation should be in collaboration with Aboriginal and Torres Strait Islander peoples.

## Dissemination

- Aboriginal and Torres Strait Islander peoples should be provided with the tools and capability to publish and disseminate their own data.

## Reuse, review and retire

- Decisions about the reuse, review and retirement of data should involve Aboriginal and Torres Strait





Islander peoples. This relates to decisions about current data assets but also includes historical data.

- Entities that are accredited data service providers will ensure that data linkage that includes any data involving or affecting Aboriginal and Torres Strait Islander people, has been supported by appropriate engagement with Aboriginal and Torres Strait Islander people, as required under the National Statement on Ethical Conduct in Human Research.
- Aboriginal and Torres Strait Islander peoples should be able to set their licensing agreements, and exercise their patents, trademarks, designs and plant breeders' rights, to maintain and protect their traditional knowledge and traditional cultural expressions ([Commonwealth of Australia 2024](#), pp. 27-29).

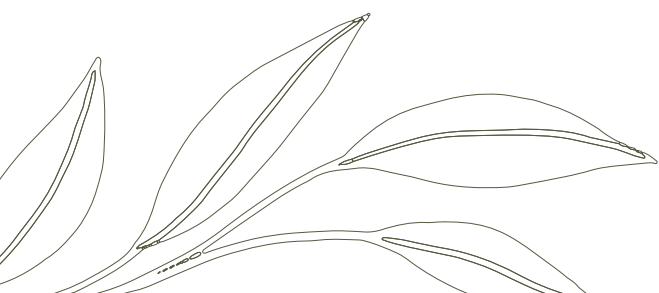
It can be observed that the word 'should' appears at every stage of the data ecosystem rather than 'will' or 'must' and it is worth repeating the caveat that the Framework is intended to implement and embed those areas of data governance where the objectives of the Indigenous data sovereignty movement and the Australian government align.

A lack of inclusive data systems to support the inclusion of Indigenous peoples in data governance has been noted ([Commonwealth of Australia 2024](#)). In January 2024, the Productivity Commission completed a review of the National Agreement on Closing the Gap. Of direct relevance to this paper are the Commission's findings in relation to Priority Reform 4: shared access to data and information at a regional level. The Commission directly addressed the issue of Indigenous data sovereignty, noting that Aboriginal and Torres Strait Islander peoples overwhelmingly viewed Priority Reform 4 as moving toward that. However, the National Agreement does

not specifically mention Indigenous data sovereignty or commit governments to embedding Indigenous data governance ([Productivity Commission 2024a](#), p. 134). That said, there is evidence that the states and territories are actively engaging with the issue and developing strategies to implement the principles of Indigenous data sovereignty, although these are at different stages ([Productivity Commission 2024b](#), p. 66). The Commission noted that the Agreement is a living document that can be updated to reflect shared priorities, progress and feedback from Aboriginal and Torres Strait Islander peoples ([Productivity Commission 2024a](#), p. 180). To that end, the Commission recommended that:

The Agreement should be amended to explicitly include IDS as part of the outcome statement for Priority Reform 4. This should be accompanied by other changes, including:

- adopting the definitions of Indigenous data sovereignty and Indigenous data governance, as set out by the Maïam nayri Wingara Indigenous Data Sovereignty Collective
- recognising that IDS is a multifaceted, long-term objective to be achieved by Aboriginal and Torres Strait Islander peoples
- recognising that IDS is necessary for Aboriginal and Torres Strait Islander peoples to determine and make decisions about their priorities and development
- committing governments to partnering with Aboriginal and Torres Strait Islander organisations and communities to embed IDG. This should include specific commitments to:
  - o incorporate IDG into existing data systems to empower Aboriginal and Torres Strait Islander peoples to decide what, how and why Indigenous





- data are collected and managed across the data lifecycle
- o strengthen the technical and administrative data capability of Aboriginal community-controlled organisations and build the Indigenous data capability of government and non-Indigenous organisations
  - o invest in developing Indigenous data infrastructure that enables communities to develop, manage and use their own data collections ([Productivity Commission 2024b](#), p. 162).

## ATSIDA principles

The Aboriginal and Torres Strait Islander Data Archive (ATSIDA) was established to collect and preserve fragmented and dispersed research data relating to Aboriginal and Torres Strait Islander peoples to make them available for further research, thereby reducing the response burden on Indigenous communities ([ATSIDA 2024a](#)).

ATSIDA seeks to identify and acquire material within the following areas:

- Discipline coverage: at the broadest level, datasets and other electronic resources relating to Aboriginal and Torres Strait Islander studies, in particular datasets about communities, individuals or groups of individuals but including demographic, health and other broad studies.
- Geographical coverage: datasets concerning Australia and its islands.
- Temporal coverage: there are no restrictions on temporal coverage.
- Time series and panel data: datasets are sought that create or add to a time series and/or panel survey.
- Thematic coverage: datasets that assist in the creation of a coherent body of materials relating to

a particular discipline, field of enquiry or cultural group or region (e.g. health; nutrition; Eora, Sydney or Pitjantjatjara, Central Australia) ([ATSIDA 2024b](#)).

An important part of their work is the repatriation of material to Aboriginal and Torres Strait Islander communities through a recognised cultural centre or community organisation ([ATSIDA 2024c](#)). To guide their work, ATSIDA developed protocols that are governed by three overarching principles:

## Respect

Aboriginal and Torres Strait Islander peoples and culture are respected.

Aboriginal and Torres Strait Islander peoples are involved in decision-making about research data managed in the data archive.

The rights and interests of Aboriginal and Torres Strait Islander peoples and researchers are respected.

## Trust

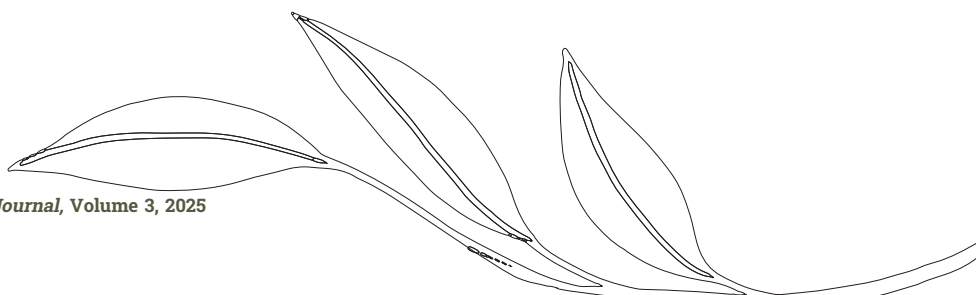
Datasets are preserved in a secure and trusted data archive.

Strong reciprocal relationships are made with Aboriginal and Torres Strait Islander peoples, communities and collecting institutions.

Datasets deposited into ATSIDA are managed according to cultural protocols.

The moral rights of the original researcher will be maintained as per the intent of the Australian Copyright Act 1968. Specifically:

- the right of attribution of authorship





- the right against false attribution of authorship
- the right of integrity of authorship.

### Engagement

ATSIDA seeks to ensure the return of Indigenous knowledge that is documented in research projects.

ATSIDA will provide a facility to ensure ongoing and timely access to materials.

ATSIDA encourages and promotes use of its data archive to stimulate new research ventures and insights that benefit Aboriginal and Torres Strait Islander communities (ATSIDA 2024d).

### OCCAAARS Framework

In 2022 Trudgett and colleagues (2022) conducted a systematic literature review of published studies on Indigenous data sovereignty. They identified principles of data governance from Canada, New Zealand, Australia and the 2017 Indigenous Data Sovereignty Symposium to develop a framework comprising eight principles, as shown in Table 4. The authors acknowledged that these principles anchor back to the rights articulated by the

Maiam nayri Wingara Indigenous Data Sovereignty Collective (Trudgett et al. 2022).

### Maiam nayri Wingara principles

Following the Indigenous Data Sovereignty Summit held in 2018, the Maiam nayri Wingara Indigenous Data Sovereignty Collective released a communique asserting Indigenous peoples’ rights to:

- 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 empower sustainable self-determination and effective self-governance
- data structures that are accountable to Indigenous peoples and First Nations
- data that are protective and respect individual and collective interests (Maiam nayri Wingara 2018).

The first of these principles is reflected in the data lifecycle approach but collectively the principles

|   |  |
|---|--|
| <b>Ownership</b>                            | The explicit ownership of data by First Peoples and/or organisations.  |
| <b>Control</b>                              | Where Indigenous peoples lead, hold power and are in control; cultural values, principles, approaches, and methods prevail. It does not exclude the involvement of others, but only as far as usefulness. Involvement of others is by invitation only.   |
| <b>Custodianship</b>                        | Refers to the concept of holding and stewarding data in their raw form, as well as the narrative. Custodianship holds significant responsibility for chartering the data along their intended path, with their intended spirit and within their intended place.  |
| <b>Access</b>                               | Indigenous people can find and obtain disaggregated and relevant data about themselves at individual, community and cohorts levels.  |
| <b>Accountability to Indigenous peoples</b> | Refers to the data, in and of itself, as well as the data users to answer to First Peoples, take responsibility for data use and outcomes, and provide explanation to Indigenous peoples. This may include the data structures, the use and nesting of data within the public domain and the continued use of data in research, policy and social domains. |
| <b>Amplify the voice of the community</b>   | Refers to the requirement for data to represent upwards and outwards, the voice and experience of community, the determined needs of community and the contextualised analysis of data by community.   |
| <b>Relevant and reciprocal</b>              | Relevant refers to useful data which support community to make good decisions and reciprocal refers to the data structures, metadata and data, providing a platform for giving back to community. Data collected for community good and community need; not just for data’s sake or Government-determined stake.   |
| <b>Sustainably self-determining</b>         | Refers to the continued use and operationalisation of data, metadata, data structures, resources and interests that affect self-determination beyond their immediate intent.   |

**Table 4: Ownership, Control, Custodianship, Access, Accountability, Amplify, Relevant, Sustainability (OCCAAARS) framework (Trudgett et al. 2022)**





encompass both governance of data and data for governance.

The Maiam nayri Wingara principles are used in the governance processes of the Mayi Kuwayu Study, which is facilitated by the Aboriginal and Torres Strait Islander Health Program within the National Centre for Epidemiology and Population Health, Research School of Population Health, at the Australian National University. Oversight by the research governance team includes members of key Aboriginal and Torres Strait Islander organisations (Lovett et al. 2020, p. 13).

This national longitudinal study is investigating the health and wellbeing of Aboriginal and Torres Strait Islander adults in Australia. Mayi Kuwayu began collecting data from voluntary participants in 2015 through questionnaires designed to elucidate how Aboriginal and Torres Strait Islander cultures and cultural domains interact directly and indirectly across health and wellbeing. In 2019, the Mayi Kuwayu Study team established a data governance committee to independently assess applications for data use subject to the Maiam nayri Wingara Indigenous data sovereignty principles. Applicants must demonstrate the application of Indigenous data sovereignty principles in their proposals and show that the proposal has appropriate ethical approval and community engagement. Proposals must also conform to AIATSIS and other relevant legal and ethical research standards (Lovett et al. 2020).

The Maiam nayri Wingara principles also underpin the Kulay Kalingka study into Aboriginal and Torres Strait Islander peoples' cancer experiences (Wells et al. 2023). In addition, the Department of Communities and Justice commissioned an investigation into mobility as a key driver of

overcrowding and other housing issues in New South Wales from Inside Policy (a group of consultants specialising in developing policy advice) (Inside Policy 2023). The Inside Policy 'Closing the Loop' report acknowledged Indigenous data sovereignty and applied the Maiam nayri Wingara principles throughout the project (Inside Policy 2023).

The Maiam nayri Wingara principles are reflected throughout the AIATSIS *Code of Ethics for Aboriginal and Torres Strait Islander Research* with the explicit statement that the Code requires:

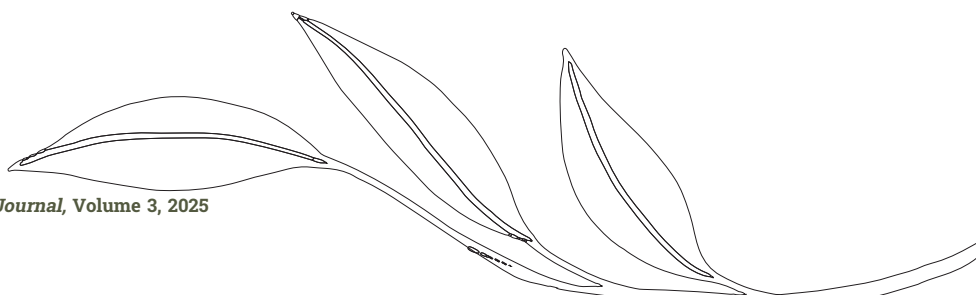
*adherence to the principles of Indigenous data sovereignty and governance and the emerging theories and practice that underpin it. Indigenous data sovereignty both recognises the rights of Indigenous peoples to control the use of their data, wherever it is held (governance of data), and the importance of access to data for Indigenous decision making and self-determination (data for governance) (AIATSIS 2020, p. 18).*

The AIATSIS Code is structured according to four principles that underpin ethical and responsible Aboriginal and Torres Strait Islander research:

- Indigenous self-determination
- Indigenous leadership
- Impact and value
- Sustainability and accountability (AIATSIS 2020, p. 12).

Similarly, the Maiam nayri Wingara principles are reflected in the National Health and Medical Research Council's *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders* (NHMRC 2018). The Guidelines are structured around six core values:

- spirit and integrity



- cultural continuity
- equity
- reciprocity
- respect
- responsibility

These values ensure that human research undertaken with Aboriginal and Torres Strait Islander people and communities:

- respects the shared values of Aboriginal and Torres Strait Islander peoples
- is relevant for Aboriginal and Torres Strait Islander priorities, needs and aspirations
- develops long-term ethical relationships among researchers, institutions and sponsors
- develops best practice ethical standards of research (NHMRC 2018, p. 3).

The Maïam nayri Wingara principles have been mapped to elements of both the AIATSIS Code of Ethics and the NHMRC Guidelines in the table in [Appendix 1](#).

## Discussion

There is a great deal of overlap and similarity between the various frameworks presented here. For example, the Maïam nayri Wingara principles match very closely with the CARE principles and the Five Safes framework as modified by [Rose and colleagues \(2023\)](#), demonstrating homologous elements within each of these contexts.

A common theme throughout the frameworks or principles described in this paper is for Indigenous control over data that are based on Indigenous world views and beneficial to Indigenous peoples. This means that a research project that is Indigenous led will be asking different questions and collecting

different types of data. These often focus on strengths within Indigenous cultures and communities rather than focusing on problems. For example, the Mayi Kuwayu longitudinal study of Aboriginal and Torres Strait Islander wellbeing focuses on cultural links to health and wellbeing. Before answering any questions related to their health, respondents are asked over 30 questions about cultural identity and responsibilities, language and connections with family and community ([Mayi Kuwayu National Study of Aboriginal and Torres Strait Islander Wellbeing 2024](#)).

Research undertaken by [Wright and colleagues \(2022\)](#) in several communities in Central Australia examined the relationship of Aboriginal family wellbeing to social and cultural determinants. The study involved 639 Aboriginal people who had participated in the Mayi Kuwayu study and involved further workshops with community participants. The analysis and interpretations of findings involved Aboriginal organisations, their Aboriginal directors and community researchers. Wright and colleagues noted that public health and primary healthcare developments increasingly recognise the importance of family in the health of individuals and that families provide the social and emotional support needed to foster children's development. The study examined household composition as one of the factors affecting family functioning and found that 'living in a multigenerational or extended family household was associated with higher family functioning compared with living in nuclear household.' The directors of one of the communities suggested that 'households containing multigenerational or extended family may be in a better position to facilitate cultural knowledge transfer and teaching and use of Aboriginal language than less diverse households' ([Wright et al 2022](#), p. 8). However, primary healthcare experts argue for reducing overcrowding and household sizes as a



means of reducing high infection rates of common preventable diseases. A more holistic approach is needed that considers family, culture and environmental health as factors contributing to wellbeing (Wright et al. 2022).

One of the community directors associated with this study provided another example of competing priorities between service providers and Indigenous peoples:

*I feel we are living and doing this culture work in our family programs at Waltja. We start our work with young people in the bush. We take them on Country and sit them down. We give them space, and we teach them culture by being on Country. But it's always hard to get this recognised by our funders. We can get a program to address alcohol easily, but what we need is a healing pathway back to our culture, back to the community and back to our Elders' teaching (Wright et al. 2022, pp. 6 – 8).*

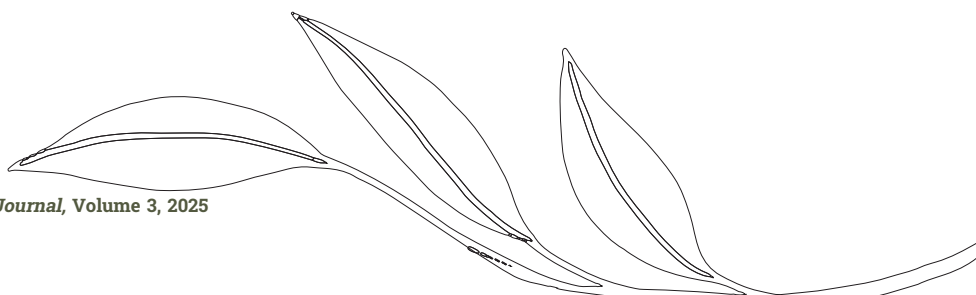
An article published on the role of Aboriginal and Torres Strait Islander fathers used data recorded in the Longitudinal Study of Indigenous Children to report that 'learning about Indigenous culture, identity and family are crucial aspects of Indigenous culture that will help children grow up strong' (Prehn et al. 2021, p. 601). The ways in which culture is passed from fathers to children were quite diverse and included traditional food gathering practices; yarning and storytelling; and learning about family, including the extended family and 'knowing who your mob is' (Prehn et al. 2021, p. 605).

The authors noted that there is very little published literature on Indigenous men and even less on Indigenous fathers and fatherhood in Australia; there was, however, a strong discourse generally portraying

Indigenous men in a negative light as incompetent or neglectful, or worse, as low-achieving alcoholics (Prehn et al. 2021). By drawing on data recorded in the Longitudinal Study on Indigenous Children, where different questions were asked of survey participants, a different picture of Indigenous fatherhood emerges. This study is an Australian government-funded survey managed by the Department of Social Services and guided by a steering committee of experts in the fields of Indigenous research, early childhood, education and health. The survey began in 2008 with data gathered from nearly 2,000 Indigenous families with children in two cohorts: six to 18 months and three-and-a-half to five years. Data have continually been added to the survey and key research questions are added as the cohorts move through childhood and into adolescence (Department of Social Services 2024). Reflecting on the survey in 2014, Professor Maggie Walter described a critical event that had occurred 10 years earlier:

*The steering committee, led by its Indigenous members, requested a redraft of the proposed study's research questions. These new questions, we argued, needed to more directly reflect Indigenous realities and perspectives as well as the feedback from the community consultations, and to more clearly articulate the benefit of the study to the children and their families (DSS 2024, p. 8).*

The Department's willingness to agree to this request makes the study unique in the long history of Aboriginal research in Australia. The Indigenous research framework affected the research questions, design, data collection and analysis practices. In addition, the steering committee was able to extend the initial data collection timeline by arguing that, for the data collection to be successful, it was essential to build trust with the survey participants and that meant taking time to develop relationships (Skelton et al. 2014).





In another example, the Yawuru native title holders around Broome had reached an agreement with the Western Australian government and the Shire of Broome in 2010 to finalise native title claims in the area. The global agreement allowed funds for capacity building, economic development and social housing, among other things, but with a very short timeframe for crucial decision-making on how the funds were to be allocated. To inform those decisions, the Nyamba Buru Yawuru (Nyamba Buru Yawuru 2020) conducted its own population survey of Indigenous households in Broome. The census data to which the Yawuru had access were not specific enough to meet their needs, so in 2011 the Yawuru recruited a survey team of 20 local Aboriginal people to establish, via questionnaires compiled through face-to-face interviews, a comprehensive demographic database for the Indigenous population of Broome, with a critical focus on housing issues. Once the data had been collected, GIS technology was used to map the locations of Indigenous households. This was overlaid with data showing the locations of state-owned houses and houses on the Aboriginal Lands Trust lands as well as public transport routes. The mapping had

*significant implications for the location of current facilities and services in terms of their physical accessibility to Indigenous residents. [This means] that any consideration of where to best locate services within Broome can now be informed by a precise measure of this accessibility, and that this can be adjusted to address the needs component parts of the population, such as different age groups (Taylor et al. 2012, p. 22).*

The mapping highlighted the lack of access to public transport – less than 20% of residents lived within 400 metres of a bus stop. This, combined with a relatively

low rate of car ownership, meant that many people relied on taxis for essential journeys for shopping or medical care. Armed with this very specific data, Nyamba Buru Yawuru was able to lobby for alterations to the bus routes. Similarly, the survey found that many Indigenous peoples living in state-owned housing had maintenance issues that had needed to be addressed for some time and the Nyamba Buru Yawuru was able to make representation on their behalf.

Peter Yu, former Chief Executive Officer of Nyamba Buru Yawuru, described the importance of the Yawuru population survey and observed that ‘the power of data in Aboriginal hands has the potential to have several important consequences for Broome and surrounding communities’ (Yu 2012, p. 6). It can provide:

- an informed basis for decision-making and for dialogue with government and industry
- a baseline to measure impacts of economic and social change
- a basis of accountability for investment for Aboriginal development in the region.

He concluded that:

*whilst the power over data collection and analysis remains in the hands of government the narrative about Indigenous people’s place in the Australian nation will continue to be one of deficit, disadvantage and dysfunction. And the policy prescriptions flowing from that narrative will continue to fail Indigenous people and the nation.*

*Only when Indigenous people are resourced to collect and analyse data and tell a far more compelling story will we see the emergence of genuine Indigenous self-determination in Australia (Yu 2012, p. 7).*





## Conclusion

As an Indigenous-led research organisation, Ngangk Yira Institute for Change is committed to recognising Indigenous data sovereignty and implementing Indigenous data governance strategies to give effect to it. Ngangk Yira works closely with an Aboriginal advisory board, an Elders council and the Kaadaninny Aboriginal Advisory Committee; however, it has also established an Indigenous Data Governance Committee tasked specifically to deal with data governance issues.

Ngangk Yira's research is framed by *Wongi mi bardup - doing it our way. Together, we have the solutions*, which means that all research conducted through the Institute enacts the five Indigenous data sovereignty principles outlined in *Maiam nayri Wingara* throughout the data ecosystem of its research. Further governance structures and processes are in place to ensure that the Five Safes and CARE and FAIR principles are applied. A guide has been developed for research staff to make clear what is expected at each of the data collection and storage, analysis and dissemination phases of their work.

A continuing area of complexity involves the extent to which Ngangk Yira participates in important and crucial research to address contemporary issues by drawing on Indigenous administrative, governmental or archival data that is de-identified and aggregated in accord with the rules and privacy constraints imposed by government bodies. Over the past 15 years, administrative data governance groups (e.g. Australian Bureau of Statistics, AIHW and state and national health departments) involving Indigenous data custodians have made inroads into ensuring that Indigenous data can be accessed and linked in ways

that are determined by Indigenous governance groups to answer many questions that were previously taken from Indigenous peoples.

Ngangk Yira urges the custodians of this data to adopt the InDatOCS model of Indigenous data governance to address 'the unique and ongoing situation facing Indigenous peoples in Australia with regard to the restitution of their rights and interests in data that has been and continues to be generated by and about them following the assertion of sovereignty by Britain over the continent of Australia' (Rose et al. 2023, pp. 23-24). In the meantime, Ngangk Yira continues to work closely with the Indigenous Data Governance Committee to mitigate any risks that these data may present.

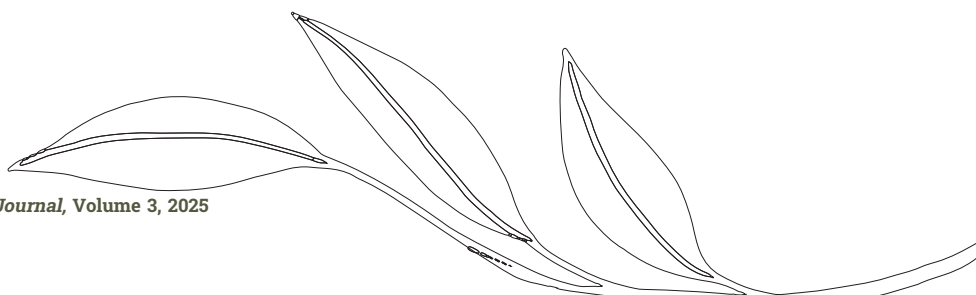
Indigenous data sovereignty is about Indigenous control over the 'who, what, when, where and why' of the collection, use and dissemination and storage of Indigenous data. While the ultimate objective of data sovereignty might be 'by mob, for mob', at this stage not all communities have the technical infrastructure, time and skills to enact this. However, 'securing the right research expertise and steering the course are also important exercises of data sovereignty' (Rodriguez-Lonebear 2016).

## Author contributions

All authors were responsible for conceptualisation of the study. R. Farrell undertook data research and drafted all versions of the manuscript with support from R. Walker. Each version was reviewed by all authors. All authors contributed to and approved the final manuscript.

## Declaration of interest

The authors declare no competing interests.





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## Author biographies

Professor Rhonda Marriott AM, Pro Vice Chancellor, Ngangk Yira Institute for Change, Murdoch University is matrilineally descended from Nyikina people with family connections to Ah Chees, Watsons, Hunters and Archers. Professor Marriott AM, a registered nurse and midwife, has extensive senior university leadership and translational research experience. She champions translation of Aboriginal-led, co-designed family (*moort - yorgas, maaman and koolangas*) research, evidence and outcomes into national policy and practice to ensure system change to strengthen Aboriginal families' futures through transformational research. As PVC for the Ngangk Yira Institute for Change, she has drawn together a passionate and capable team of Aboriginal and non-Indigenous researchers for meaningful research partnerships with Elders and Aboriginal communities across Western Australia.

Dr Rita Farrell is a historian with 20 years' experience working in native title research. She was a Senior Research Fellow at Ngangk Yira Institute for Change for five months in 2024 assisting the Institute in the implementation of Indigenous data sovereignty and Indigenous data governance.

Professor Juli Coffin is a proud Aboriginal woman, with traditional ties to her grandparents' Nyangumarta Country in the Pilbara, with a passion for advocacy and betterment of outcomes for Aboriginal young people and communities. She is a prominent Aboriginal researcher with expertise in cultural security,

education and research across a diverse range of settings, including chronic diseases, community development, health promotion and equine psychotherapy. She is currently strengthening evidence of culturally secure social and emotional wellbeing through the Kimberley Yawardani Jan-ga Equine Assisted Learning research program, which has engaged over 2,000 Aboriginal young people and 50 stakeholders since its inception.

Professor Tracy Reibel is the Stan Perron Charitable Foundation Chair and Systems and Policy Lead at the Ngangk Yira Institute for Change. Professor Reibel investigates healthcare and health system responses to providing maternal and infant care and is a strong advocate for change. Since 2008, she has worked as an ally with Aboriginal colleagues, Elders and community members to identify the systems changes required to achieve Aboriginal-led approaches that support the health and wellbeing of First Nations families. This includes embedding into maternity and child healthcare services models of care that are culturally safe, support personal needs and respect culture as the bedrock of Aboriginal social and emotional wellbeing.

Professor Roz Walker is a Senior Principal Research Fellow and Director, Coolamon Research and Advocacy Centre at Ngangk Yira Institute for Change, Murdoch University, which aims to address issues in environmental and planetary health to improve outcomes in maternal, child and adolescent health, mental health and social and emotional wellbeing in Aboriginal communities. She has extensive experience in addressing inequities in health, working with Aboriginal organisations and community groups to identify problems and develop solutions at individual, organisational and community levels, along with





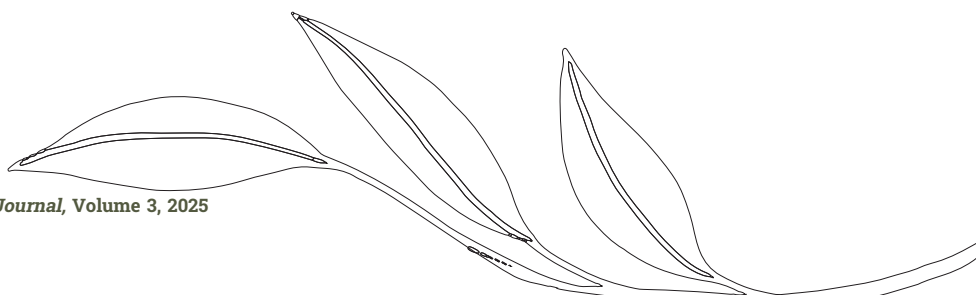
promoting system level change and individual and organisational cultural competence.

## Supplementary material

Supplementary material associated with this article can be found in the online version at <https://doi.org/10.1016/j.fnhli.2025.100072>

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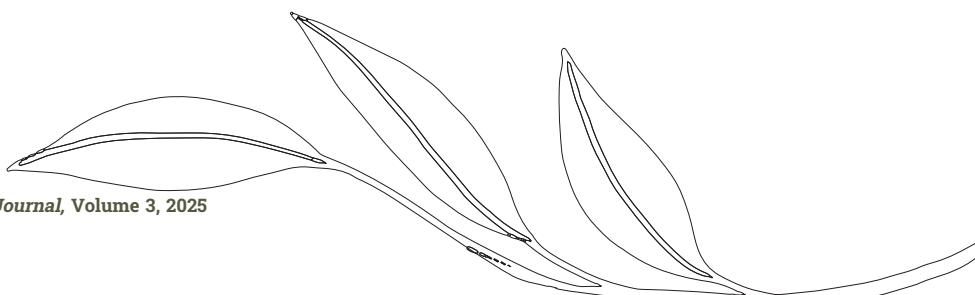


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