

# Indigenous Survivance: Sovereignty, Governance, and Health

NASEM 10 JUNE 2022

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She/Her  
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The University of Arizona is on the land and territories of Indigenous Peoples. Today, Arizona is home to 22 federally recognized tribes, with Tucson being home to the O'odham and the Yaqui.



THE UNIVERSITY OF ARIZONA

**NATIVE NATIONS  
INSTITUTE**

Founded by the Udall Foundation  
& the University of Arizona

*Strengthening Indigenous Governance*



THE UNIVERSITY OF ARIZONA

**Mel & Enid Zuckerman  
College of Public Health**

[INDIGENOUSDATA.LAB.ORG](https://indigenousdatalab.org) | [@Indigidatalab](https://twitter.com/Indigidatalab)  
[USINDIGENOUSDATA.ORG](https://usindigenousdata.org) | [@USIDSN](https://twitter.com/USIDSN)  
[GIDA-GLOBAL.ORG](https://gida-global.org) | [@GidaGlobal](https://twitter.com/GidaGlobal)



# Indigenous Peoples' Health and Well-being

1. Sovereignty matters.
2. The settler colonial project continues.
3. Colonization causes health inequities.
4. Indigenous Peoples survive, thrive, and persist.
5. **Data are our relations and are part of our healing journey.**
6. Self-determination and governance lead to healthy, vibrant communities.





How do we move institutions, from  
[extractive, transactional colonial practices] and  
[reconfigure power relationships] to put  
**Indigenous lives in Indigenous hands?**



# INDIGENOUS DATA SOVEREIGNTY

The *right* of Indigenous Peoples and nations to govern the collection, ownership, and application of their own data.

1

Derives from inherent rights to govern peoples, lands, and resources.

2

Genesis in traditions, roles, and responsibilities for the use of community held information.

3

Positioned within a human rights framework and court cases, treaties, and/or recognition.

4

Knowledge belongs to the collective and is fundamental to who we are as peoples.

See Kukutai T & Taylor J. (Eds). (2016). Indigenous Data Sovereignty. Canberra: Australian National University Press.

[USINDIGENOUSDATA.ORG](https://usindigenousdata.org) | [@USIDSN](https://twitter.com/USIDSN)

[GIDA-Global.ORG](https://gida-global.org) | [@GIDAGlobal](https://twitter.com/GIDAGlobal)

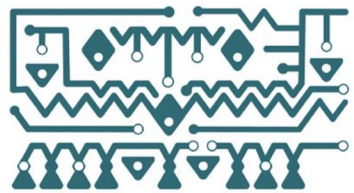
# Centering Sovereignty: The Interdependence of Nation Rebuilding and Data Rebuilding



**Carroll, Stephanie Russo, Desi Rodriguez-Lonebear, Andrew Martinez.** “Indigenous Data Governance: Strategies from United States Native Nations.”

*Data Science Journal* 18(1)p.31. DOI: 10.5334/dsj-2019-031. informed by Smith, D. 2016. Governing data and data for governance: the everyday practice of Indigenous sovereignty. In: Kukutai, T and Taylor, J (eds.), *Indigenous data sovereignty: Toward an agenda*, pp. 253–272. Canberra, Australia: Australian National University Press. DOI: <https://doi.org/10.22459/CAEPR38.11.2016.07>.

# IDSOV + IDGOV PRINCIPLES



CARE Principles  
for Indigenous  
Data Governance



## Principles of Māori Data Sovereignty

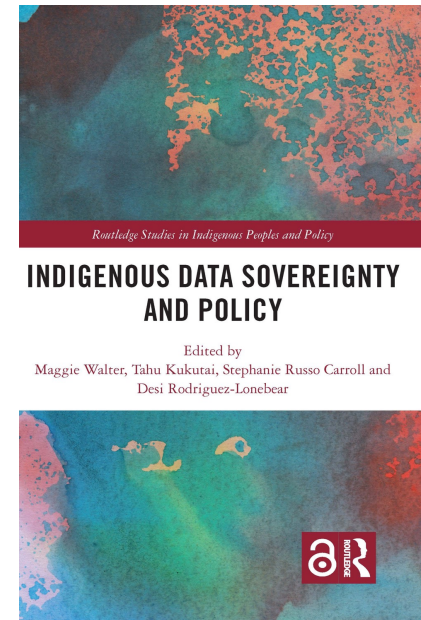
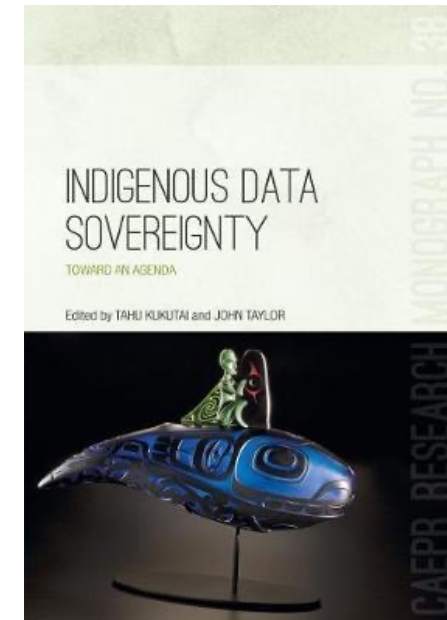
Brief #1 | October 2018

This Te Mana Rauunga (TMR) Brief provides a general overview of key Māori Data Sovereignty terms and principles.

TMR advocates for the realisation of Māori rights and interests in data<sup>1</sup>, and for the ethical use of data to enhance the wellbeing of our people, language and culture.

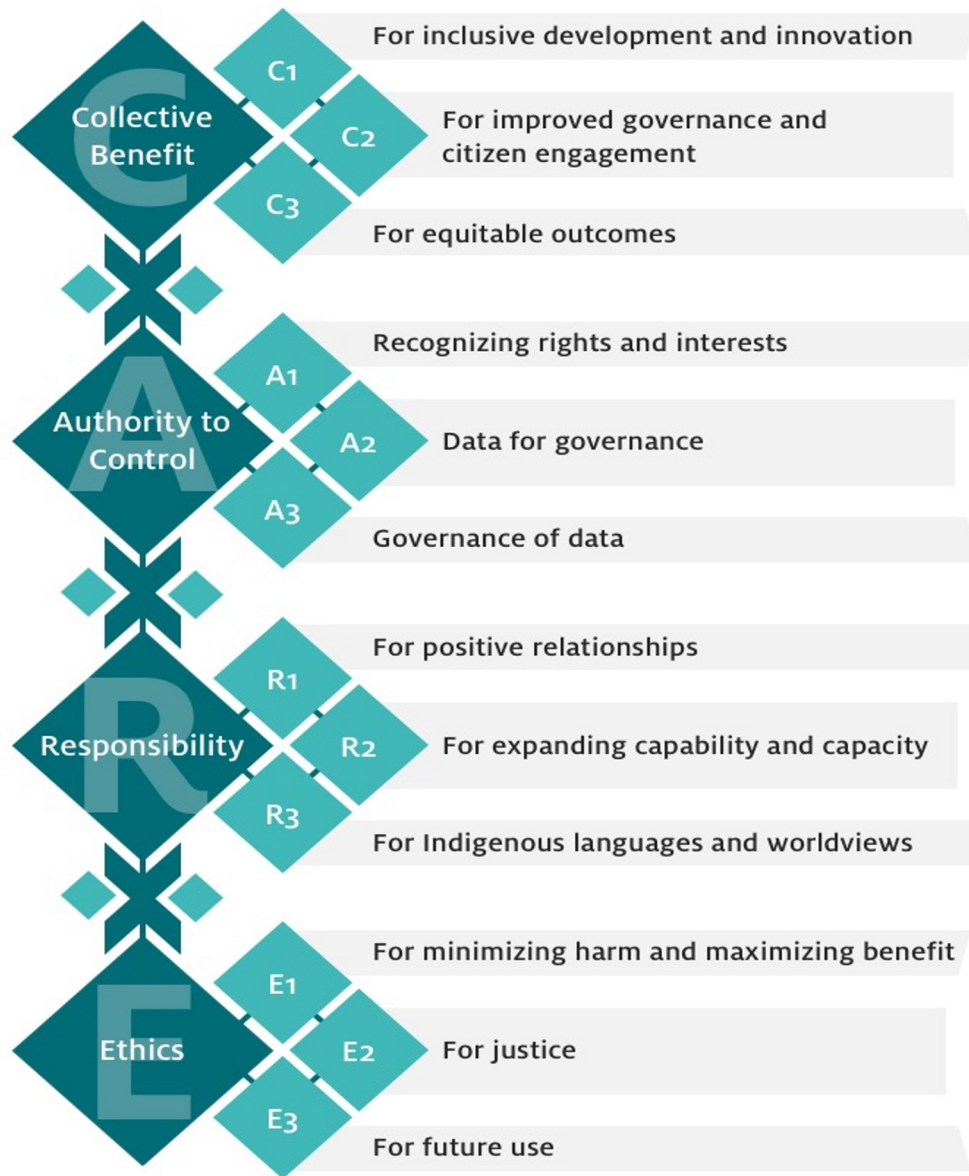
**"He rei ngā niho, he paraoa ngā kauae"**

"One must have the right principles for important endeavours."





# CARE Principles for Indigenous Data Governance



**Carroll, SC**, Garba, I, Figueroa-Rodríguez, OL, Holbrook, J, Lovett, R, Materechera, S, Parsons, M, Raseroka, K, Rodriguez-Lonebear, D, Rowe, R, Sara, R, Walker, JD, Anderson, J and Hudson, M. 2020. The CARE Principles for Indigenous Data Governance. *Data Science Journal*, 19: 43, pp. 1–12. DOI: <https://doi.org/10.5334/dsj-2020-043>

Be

**FAIR**

Findable

Accessible

Interoperable

Reusable

and

**CARE**

Collective  
Benefit

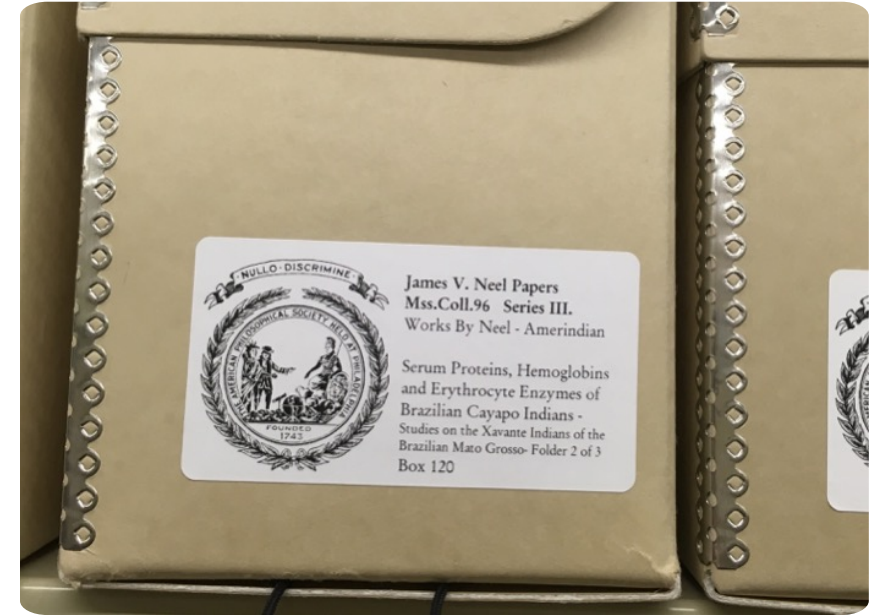
Authority  
to Control

Responsibility

Ethics



# Indigenous Knowledge & Data: Infrastructure Challenges



Every Indigenous community has enormous collections of tangible and intangible cultural material, knowledge, and data, held in archives, museums, libraries, repositories, and other online databases.



Significant information about these collections, including individual and community names and proper provenance information, is missing.



Indigenous peoples and communities are largely not the legal rights holders.



Issues of responsibility & ownership, as well as the incomplete and significant mistakes in the metadata, continue into the digital lives of this material.



There are more researchers working and collecting data and samples from Indigenous communities than ever before, generating vast amounts of new data.

# Analysis of Research Policies

*Annual Review of Genomics and Human Genetics*

## Genomic Research Through an Indigenous Lens: Understanding the Expectations

Nanibaa' A. Garrison,<sup>1,2</sup> Māui Hudson,<sup>3</sup>  
 Leah L. Ballantyne,<sup>4</sup> Ibrahim Garba,<sup>5,6</sup>  
 Andrew Martinez,<sup>6</sup> Maile Tualii,<sup>7</sup> Laura Arbour,<sup>4,8</sup>  
 Nadine R. Caron,<sup>9,10,11</sup> and Stephanie Carroll Rainie<sup>6,12</sup>



**Table 2. Comparison of Indigenous Research Guidelines**

	Canada	New Zealand	Australia	United States	Indigenous
<b>COMMUNITY ENGAGEMENT</b>					
In Protocol development	X <sup>a</sup>	X <sup>b,c</sup>	X <sup>e</sup>	-	-
Before collection of samples	X <sup>a</sup>	X <sup>b,c</sup>	-	-	X <sup>h</sup>
Respect for cultural differences embodied	X <sup>a</sup>	X <sup>b,c</sup>	X <sup>d,e</sup>	-	X <sup>h</sup>
Potential uses defined prior to sample collection	X <sup>a</sup>	X <sup>c</sup>	X <sup>d</sup>	X <sup>f</sup>	X <sup>h</sup>
Discussion of secondary uses with contributors (DI or DC)	DI <sup>a</sup> DC <sup>a</sup>	DC <sup>c</sup>	DI <sup>d</sup>	DI <sup>f</sup>	DC <sup>h</sup>
<b>RIGHTS AND INTERESTS</b>					
Formal community approval required	X <sup>a</sup>	-	X <sup>d,e</sup>	X <sup>f</sup>	X <sup>h</sup>
Secondary uses require community approval	X <sup>a</sup>	-	X <sup>d</sup>	-	X <sup>h</sup>
Should benefit contributing population	X <sup>a</sup>	X <sup>c</sup>	X <sup>d,e</sup>	X <sup>g</sup>	X <sup>h</sup>
Clear position on commercial applications	X <sup>a</sup>	X <sup>c</sup>	X <sup>d</sup>	-	X <sup>h</sup>
Cultural review (In a culturally sensitive manner)	X <sup>a</sup>	X <sup>b,c</sup>	X <sup>d</sup>	-	X <sup>h</sup>
<b>INSTITUTIONAL RESPONSIBILITIES</b>					
Provision for withdrawal of samples (IW or CW)	IW <sup>a</sup> CW <sup>a</sup>	IW <sup>c</sup>	IW <sup>d</sup> CW <sup>d</sup>	IW <sup>f,g</sup>	CW <sup>h</sup>
Ongoing research updates to participating communities	X <sup>a</sup>	X <sup>c</sup>	X <sup>e</sup>	-	X <sup>h</sup>
Need to develop and implement Indigenous guidelines	X <sup>a</sup>	X <sup>c</sup>	X <sup>e</sup>	-	X <sup>h</sup>
Community review of study findings before release	X <sup>a</sup>	X <sup>b,c</sup>	-	-	X <sup>h</sup>
Biobanking (agreements, plans, etc.)	X <sup>a</sup>	X <sup>c</sup>	X <sup>d</sup>	X <sup>g</sup>	X <sup>h</sup>
Data sharing agreements	X <sup>a</sup>	X <sup>c</sup>	X <sup>d</sup>	X <sup>f</sup>	X <sup>h</sup>
<b>ETHICAL/REGULATORY OVERSIGHT</b>					
Possible collective harm (e.g. group discrimination) discussed as part of informed consent process	X <sup>a</sup>	X <sup>b,c</sup>	X <sup>d,e</sup>	X <sup>g</sup>	X <sup>h</sup>
Sanctions for misuse of samples or data	-	-	-	-	X <sup>h</sup>

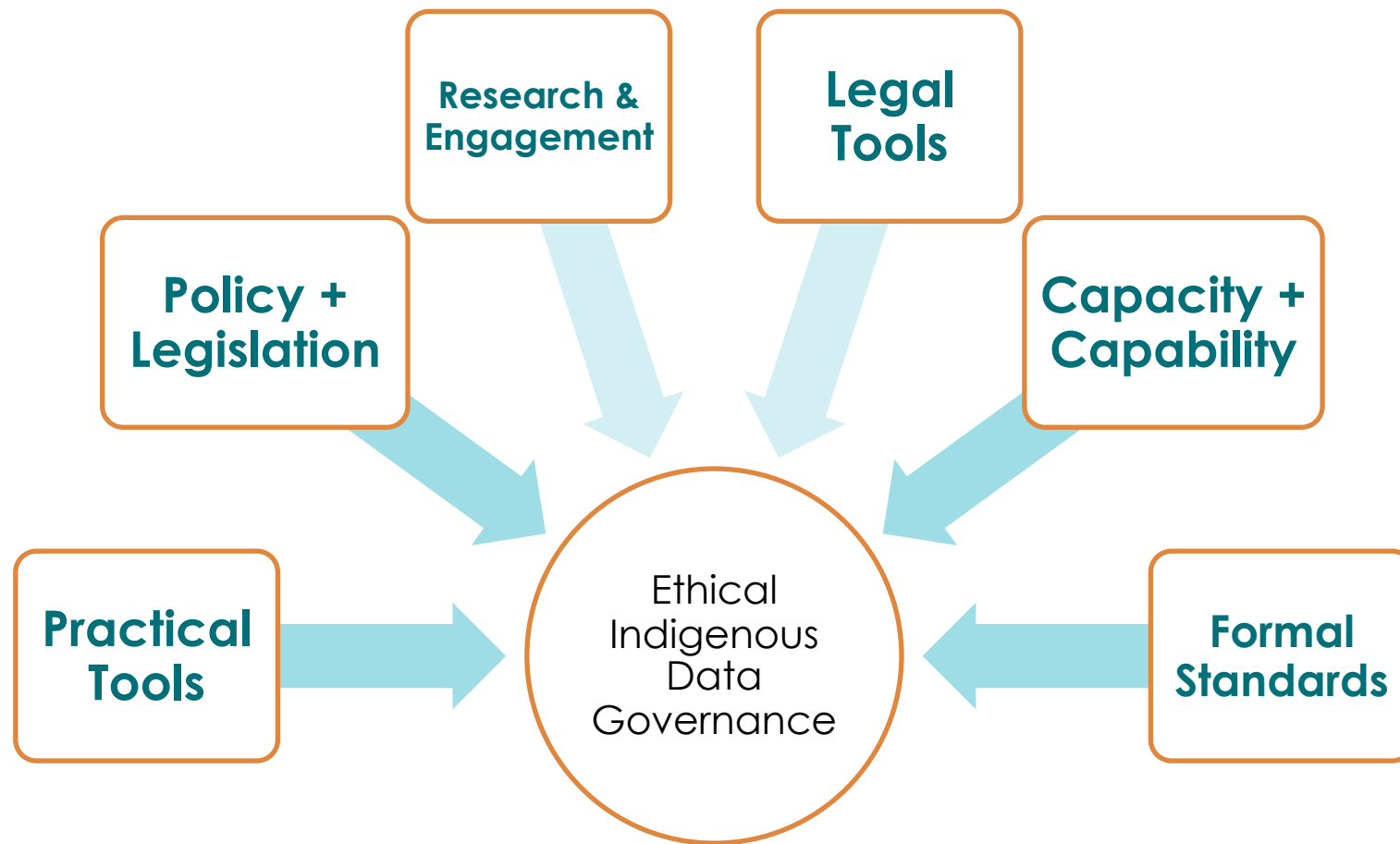
X = Discussed in reference, NO = Not referenced, IW = Individual withdrawal, CW = Community withdrawal, DI = Discussion held with individual, DC = Discussion held with community



# Nation-State Policies Incorporate IDSov

NATIONS	NATIONAL POLICY
Aotearoa New Zealand	Vision Mātauranga policy
Australia	AIATSIS code
Canada	Tri-Council policy & OCAP
United States	none

*Table 2: Overview of nations with similar colonial legacies and large Indigenous populations (all UNDRIP Signatories) federal guidelines and codes relating to Indigenous research and data governance*

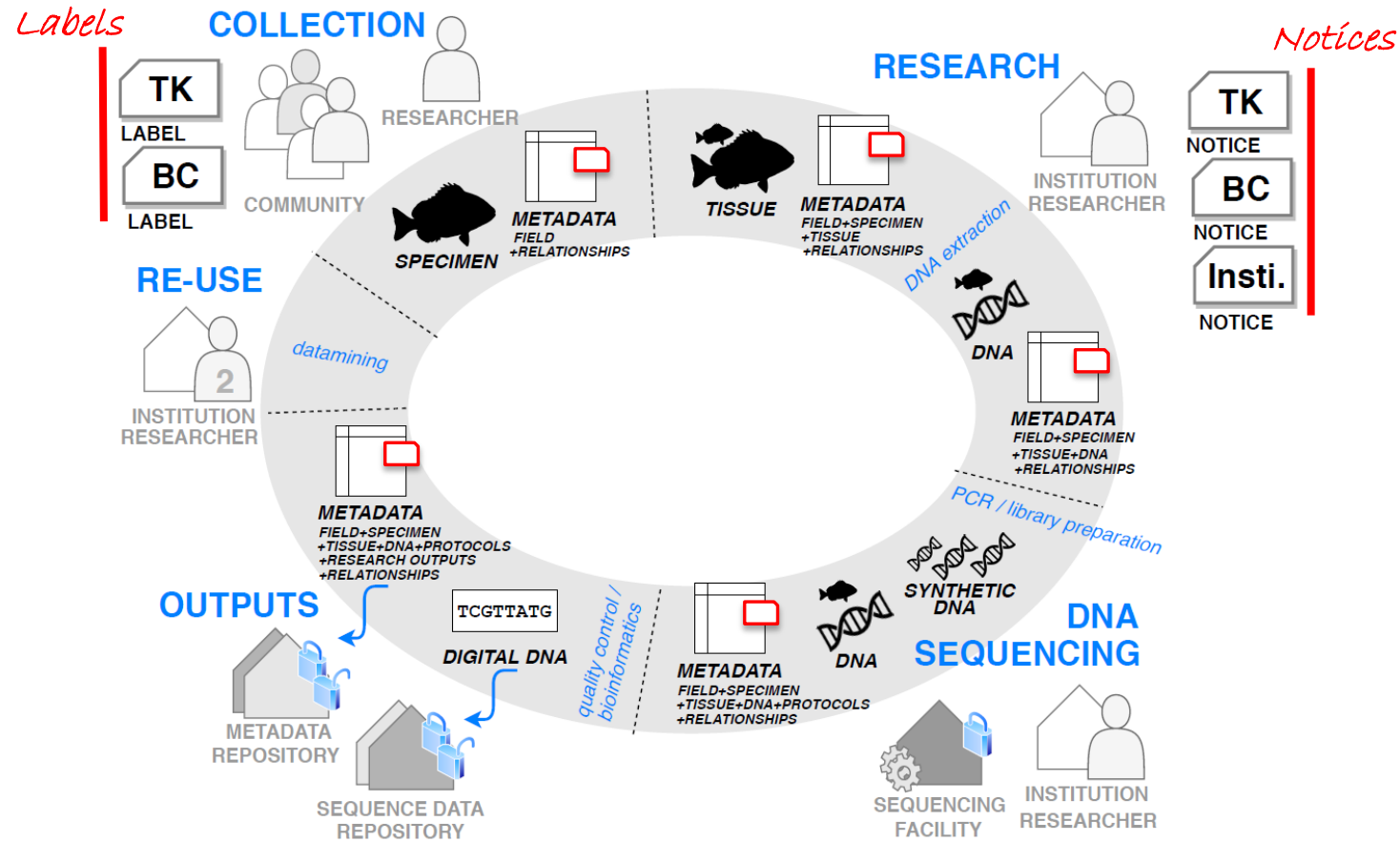


Indigenous Data Sovereignty Networks & Advocates

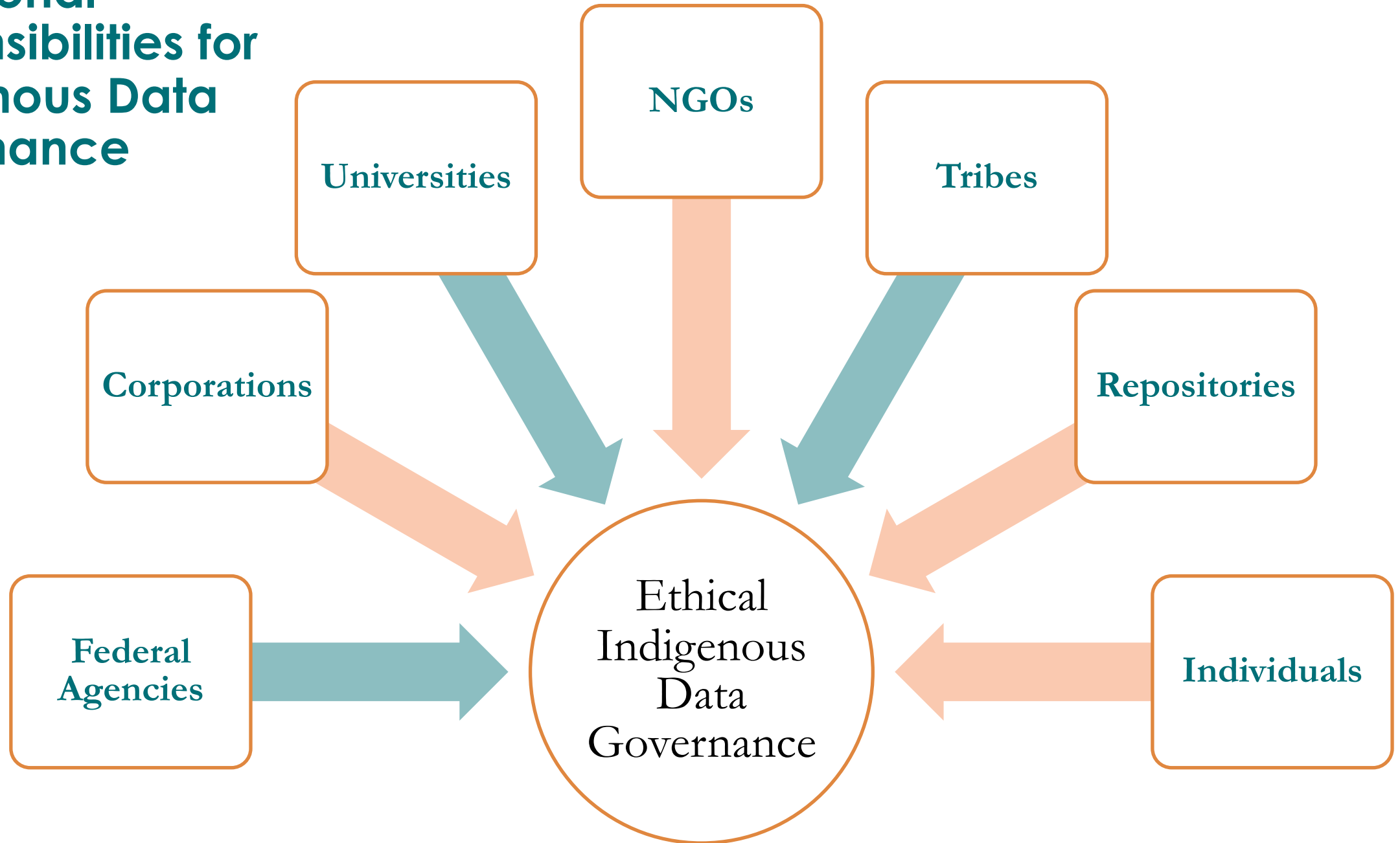
Indigenous Peoples, Nations, & Communities



# THE DATA LIFE CYCLE

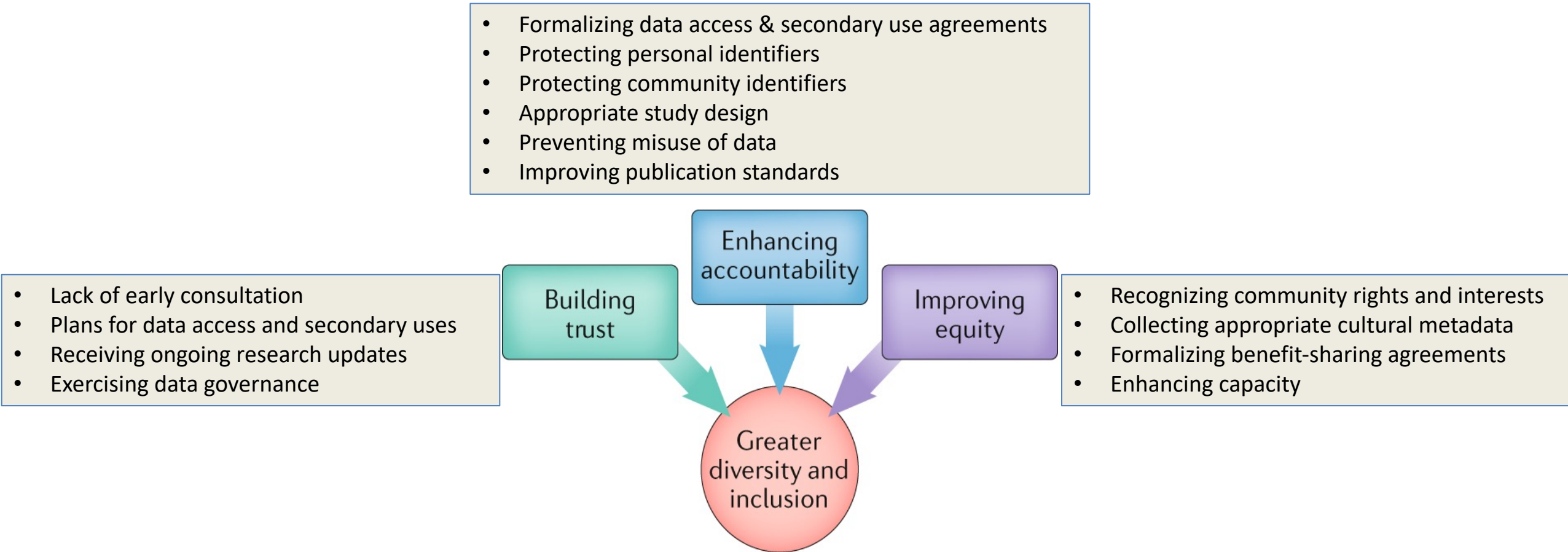


# Institutional Responsibilities for Indigenous Data Governance





# Indigenous Perspectives on Genomic Data



Hudson M et al. Rights, interests and expectations: Indigenous perspectives on unrestricted access to genomic data. *Nat Rev Genet.* 2020 Jun;21(6):377-384.

# Institutional Responsibilities for Indigenous Data Governance

## Center CARE principles in the development of data policy & platforms

- Center Indigenous Peoples in leadership and scholarship
- Enrich metadata (provenance, permissions, attribution & protocols)
- Recognize Indigenous intellectual property through appropriate authorship & acknowledgement
- Protect **both** personal and community identifiable information
- Formalize guidelines
- Track data use and reuse

# Center Indigenous Peoples and People in Leadership and Scholarship

- Use existing tribal expectations to set policy
- Seek guidance from Indigenous leadership and scholarship



PERSPECTIVE  
published: 21 March 2022  
doi: 10.3389/fgene.2022.823309

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## Using Indigenous Standards to Implement the CARE Principles: Setting Expectations through Tribal Research Codes

*Stephanie Russo Carroll<sup>1,2</sup>, Ibrahim Garba<sup>1,2</sup>, Rebecca Plevel<sup>2,3,4</sup>, Desi Small-Rodriguez<sup>5,6</sup>, Vanessa Y. Hiratsuka<sup>7</sup>, Maui Hudson<sup>8</sup> and Nanibaa' A. Garrison<sup>9,10,11\*</sup>*



# Enrich metadata

(provenance, permissions, attribution & protocols)



# Recognize Indigenous intellectual property through authorship & acknowledgement

- Who is credited for knowledge in repositories, publications, and research findings?
- Consider community contexts

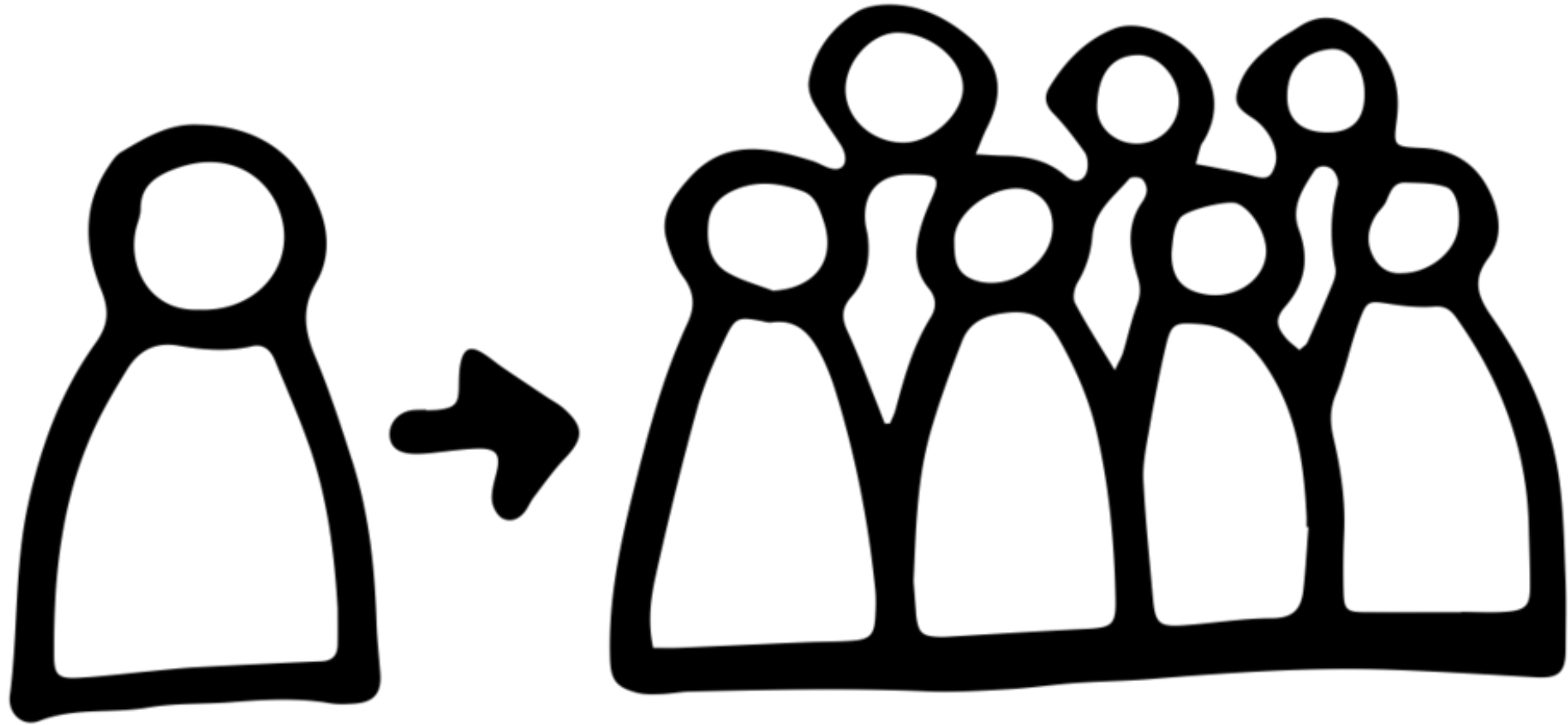
**“We have come together to declare our intention to publish ‘nothing about Indigenous peoples, without Indigenous peoples’.**

How this is specifically articulated in practice will vary by journal and nation,<sup>[1](#)</sup> but in essence, **we will reject submitted papers that concern Indigenous communities but do not acknowledge an Indigenous author or provide evidence of a participatory process of Indigenous community engagement.”**

– **Position statement: Research and reconciliation with Indigenous peoples in rural health journals (2022).** *Australian Journal of Rural Health* simultaneously with the *Canadian Journal of Rural Health* and *Rural and Remote Health*  
**<https://onlinelibrary.wiley.com/doi/10.1111/ajr.12834>**



# Protect both personal and community identifiable information



# Formalize guidelines

- UN Special Rapporteur on the right to privacy. Recommendation on the Protection and Use of Health-Related Data
- COVID19 Indigenous Data Guidelines for Research Data Alliance
- Asia-Pacific Economic Cooperation Policy Partnership on Science, Technology and Innovation Statement on Open Science
- UNESCO Recommendation on Open Science
- Education in partnership with ORCID and RDA in North America, Central America and Asia-Pacific regions
- Intergovernmental Science-Policy Platform on Biodiversity and Ecosystem Services Data Management Policy
- In Process: Earth Science Information Partners Guidelines on TRUST FAIR with CARE
- In Process: IEEE P2890 Indigenous Data Working Group on the Provenance of Indigenous Peoples Data
  
- Co-Designing Māori data governance model for all of government data (Government Chief Data Steward + Stats NZ)
- National Ethical Standards for Health and Disability Research and Quality Improvement
- Australia New Zealand Standard Research Classification: Indigenous Studies as a broad division alongside biological sciences and economics etc.; Indigenous data sovereignty as a field
- AIAITSIS Code of Ethics for Aboriginal and Torres Strait Islander Research



# AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research

## *Indigenous knowledge and data*

2.7 Indigenous peoples have the right to manage the collection, interpretation and use of their information.

- a. ownership management and communication of research data and results should be negotiated between Indigenous peoples and the researcher or other parties based on the principles of Indigenous data sovereignty and governance.
- b. processes should be agreed at an early stage for ownership, management and use of, access to, and distribution of research results. Written agreements are normally required to clarify and secure rights in data.

2.8 The contribution of Indigenous peoples' knowledge, resources and access to data should be acknowledged by ensuring ongoing ownership, control and/or access for Indigenous people to research results.

2.9 Institutions with responsibility for data access and use policies or design and management of data ecosystems should adopt Indigenous data sovereignty and governance principles.<sup>63</sup>

- a. where a conflict arises between accessibility and Indigenous peoples rights, then Indigenous peoples' rights should prevail.<sup>64</sup>
- b. researchers must be aware of and apply the international data principles of FAIR (Findable, Accessible, Interoperable and Reusable) and CARE (Collective benefit, Authority, Responsibility and Ethics).<sup>65</sup>



**Track data  
use and  
reuse**



**CGIAR Platform for  
Big Data In  
Agriculture  
Guidelines for the  
Data Cycle**

# SO WHAT NOW ....

- IDSov and IDGov links already exist across the US & CANZUS states, disciplines, and sectors
- Transforming institutions to operationalize IDGov has begun, but much left to do (infrastructure, ethics, policy, law)
- IDSov and IDGov provide HUGE opportunities to catapult institutions into doing research differently – with and for, not on behalf of – and doing innovative research
- If there are ‘trade-offs’ to be made (e.g. open data), and it involves Indigenous data, the decision-making lies with Indigenous communities

**Indigenous data belong in Indigenous hands**