

Indigenous Data Sovereignty: An Overview and Potential Application of Data Governance for CRITFC

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Citizen of the Salt River Pima-Maricopa Indian Community

Located within the traditional homelands of the Mary's River
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Ahtna, a citizen of the Native Village of Kluti-Kaah

Located on the unceded homelands of the Tohono
O'odham and Yaqui Peoples

Inter-Tribal Monitoring Data Project Annual Meeting | April 13, 2021



[USINDIGENOUSDATA.ORG](https://usindigenousdata.org)
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**Collaboratory for Indigenous
Data Governance** Research,
Policy, and Practice for
Indigenous Data Sovereignty

[INDIGENOUSDATA LAB.ORG](https://indigenousdatalab.org)
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PRESENTATION OUTLINE

- 1. Introduction and Definitions**
- 2. What are Indigenous Data?**
- 3. Indigenous Data Sovereignty**
- 4. Indigenous Data Governance**
- 5. Initial Questions and Discussion**
- 6. The CARE Principles for Indigenous Data Governance**
- 7. Indigenous Data Sovereignty and Governance in Practice**
- 8. Questions and Discussion**

Seven Truths: Indigenous Peoples and Data

- 
1. Sovereignty matters.
 2. Data are our relations.
 3. Data are critical to the exercise of tribal sovereignty and ensuring healthy, vibrant communities.
 4. Only Indigenous Peoples/nations can exercise Indigenous data sovereignty.
 5. Enacting Indigenous data sovereignty includes both data for governance and the governance of data.
 6. Tribally-driven data work requires relationships with other data actors and experts for both stewardship and expertise.
 7. Assertions of Indigenous data sovereignty spur innovation and design in data and research policy and practice.

INDIGENOUS PEOPLES SPAN THE GLOBE

370 MILLION INDIGENOUS PEOPLES WORLDWIDE
ACROSS 70 COUNTRIES – OVER 5000 CULTURES

An official definition of “Indigenous” has not been adopted by any UN-system body.

A modern understanding:

- Self-identification as Indigenous Peoples at the Individual level and accepted by the community as their member.
- Historical continuity with pre-colonial and or pre-settler societies.
- Maintain strong link to territories & surrounding natural resources.
- Distinct social, economic or political systems.
- Distinct language, culture and beliefs.
- Maintain and reproduce their ancestral environments and systems as distinctive peoples and communities.

MAINSTREAM DATA DEFINITION

Measurements or statistics **used** as a basis for reasoning, discussion, or calculation.

SELF-DETERMINATION

- + The extent that a nation is able to make and enforce its own rules, resolve disputes, problem-solve when the rules don't work as well as people might like, and establish its own governing institutions.

Sovereignty is Self-Determination.

GOVERNANCE

+ The system of values, policies and institutions by which a society manages its economic, political and social affairs through interactions within and among the state, civil society and private sector.

+ **GOVERNMENT**

An organization structure to do governance

MAINSTREAM DATA SOVEREIGNTY & DATA GOVERNANCE

+ DATA SOVEREIGNTY:

the concept that information which has been converted and stored in binary digital form is subject to the laws of the country in which it is located.

+ DATA GOVERNANCE:

refers to the ownership, collection, control, analysis, and use of data.

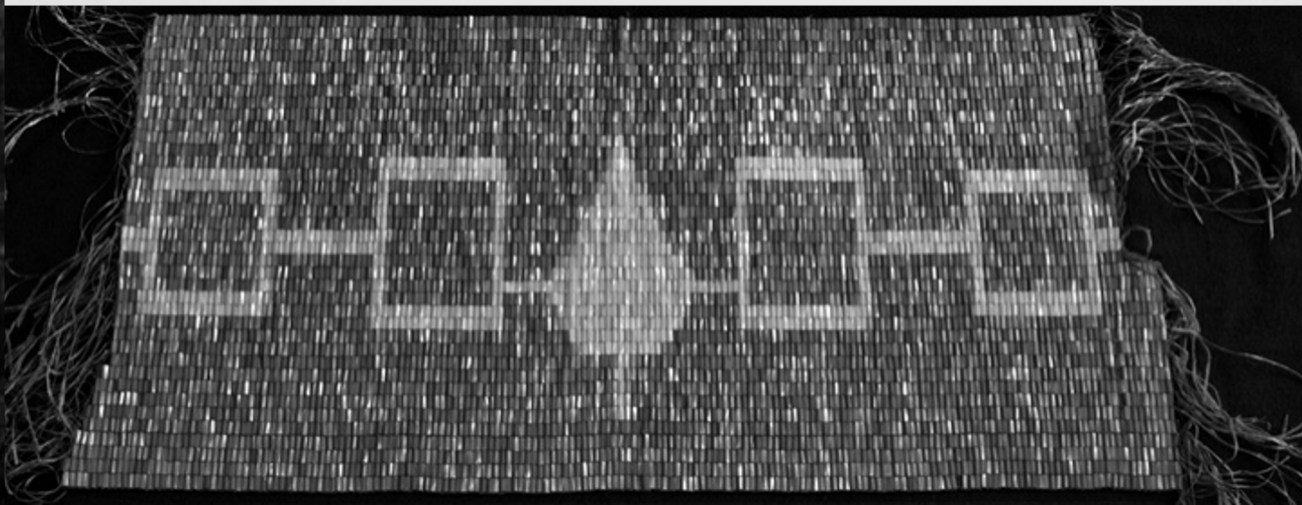
(Rouse M, 2013; <http://whatis.techtarget.com/definition/data-sovereignty>)

(The Data Governance Institute, 2015; http://www.datagovernance.com/adg_data_governance_definition/)

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OUR PEOPLES HAVE ALWAYS BEEN
DATA EXPERTS



WHAT ARE INDIGENOUS DATA?

Information, in any format, that impacts Indigenous lives at the collective and individual levels:

DATA ABOUT OUR RESOURCES AND ENVIRONMENTS

Land, water, geology, titles, air, soil, sacred sites, territories, plants, animals, etc.

DATA ABOUT US AS INDIVIDUALS

Administrative, legal, health, social, commercial, corporate, services, etc.

DATA ABOUT US AS NATIONS

Traditional and cultural information, archives, oral histories, literature, ancestral and clan knowledge, stories, belongings, etc.

Informed by British Columbia First Nations Data Governance Institute - BCFNDGI.COM

USINDIGENOUSDATA.ORG | @USIDSN

DATA CONCEPTUALIZATION AND PRODUCTION:

Settler Colonial Science

- Quantitative
- Observations made by a small group of professionals
- Synchronic data
- Objective
- Knowledge held by individuals or institution

Indigenous Science Practices/ Traditional Ecological Knowledges

- Qualitative and Quantitative
- Observers are resources users
- Diachronic data
- Subjective
- Knowledge is held by the collective

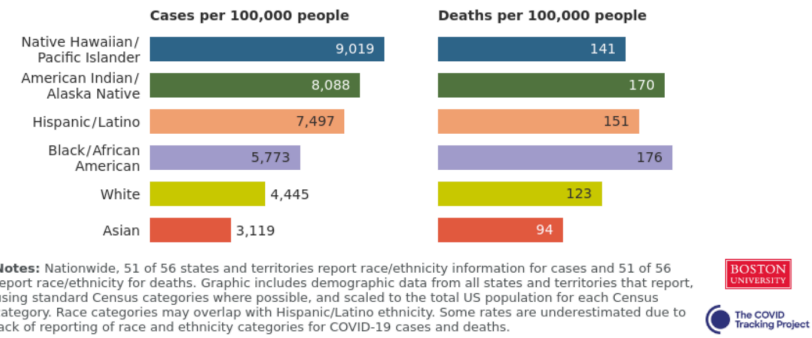
Additional information on the IHS is available at ihs.gov.

MORTALITY DISPARITY RATES

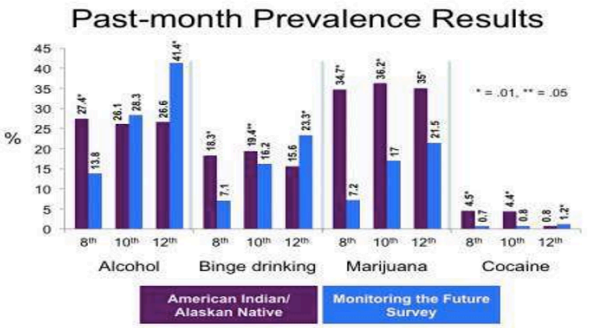
American Indians and Alaska Natives (AI/AN) in the IHS Service Area
2009-2011 and U.S. All Races 2010
(Age-adjusted mortality rates per 100,000 population)

	AI/AN Rate 2009-2011	U.S. All Races Rate - 2010	Ratio: AI/AN to U.S. All Races
ALL CAUSES	999.1	747.0	1.3
Diseases of the heart (Heart Disease)	194.7	179.1	1.1
Malignant neoplasm (cancer)	178.4	172.8	1.0
Accidents (unintentional injuries)*	93.7	38.0	2.5
Diabetes mellitus (diabetes)	66.0	20.8	3.2
Alcohol-induced	50.0	7.6	6.6

In the **United States**, through March 3, 2021, Native Hawaiians/Pacific Islanders were most likely to have contracted COVID-19. Black/African American people were most likely to have died.



Stanley LR, Harness SD, Swaim RC, Beauvais F.
Rates of substance use of American Indian students in 8th, 10th, and 12th grades living on or near reservations: update, 2009-2012.
Public Health Rep. 2014 Mar-Apr;129(2):156-63.



POLITICO MAGAZINE THE AGENDA PRO

HEALTH CARE

American Indian tribes thwarted in efforts to get coronavirus data

The CDC has turned down tribal epidemiologists' requests for data that it's making freely available to states.

UNITED STATES PRESIDENT

RACE

RACE	Percentage
WHITE	65%
LATINO	13%
BLACK	12%
SOMETHING ELSE	6%
ASIAN	3%

CNN EXIT POLL

BREAKING NEWS

CNN EXIT POLL

56:12 NEXT POLLS CLOSE

CNN

Indigenous Peoples' Health and Welfare Data Challenges in the United States

Carroll, Stephanie Russo, Desi Rodriguez-Lonebear**, Andrew Martinez. "Indigenous Data Governance: Strategies from United States Native Nations." *Data Science Journal* 18(1)p.3; doi: 10.5334/dsj-2019-031.

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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 their 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.

For more information see the US Indigenous Data Sovereignty web site usindigenousdata.org.
See also, Kukutai T & Taylor J. (Eds). (2016). Indigenous Data Sovereignty. Canberra: Australian National University Press.

INDIGENOUS DATA SOVEREIGNTY

STEMS FROM TRIBAL SOVEREIGNTY
POSITIONED WITHIN

FEDERAL AND STATE RECOGNITION

COURT CASES

TREATIES

UNITED NATIONS DECLARATION ON THE RIGHTS OF INDIGENOUS
PEOPLES

PRESENTATION OUTLINE

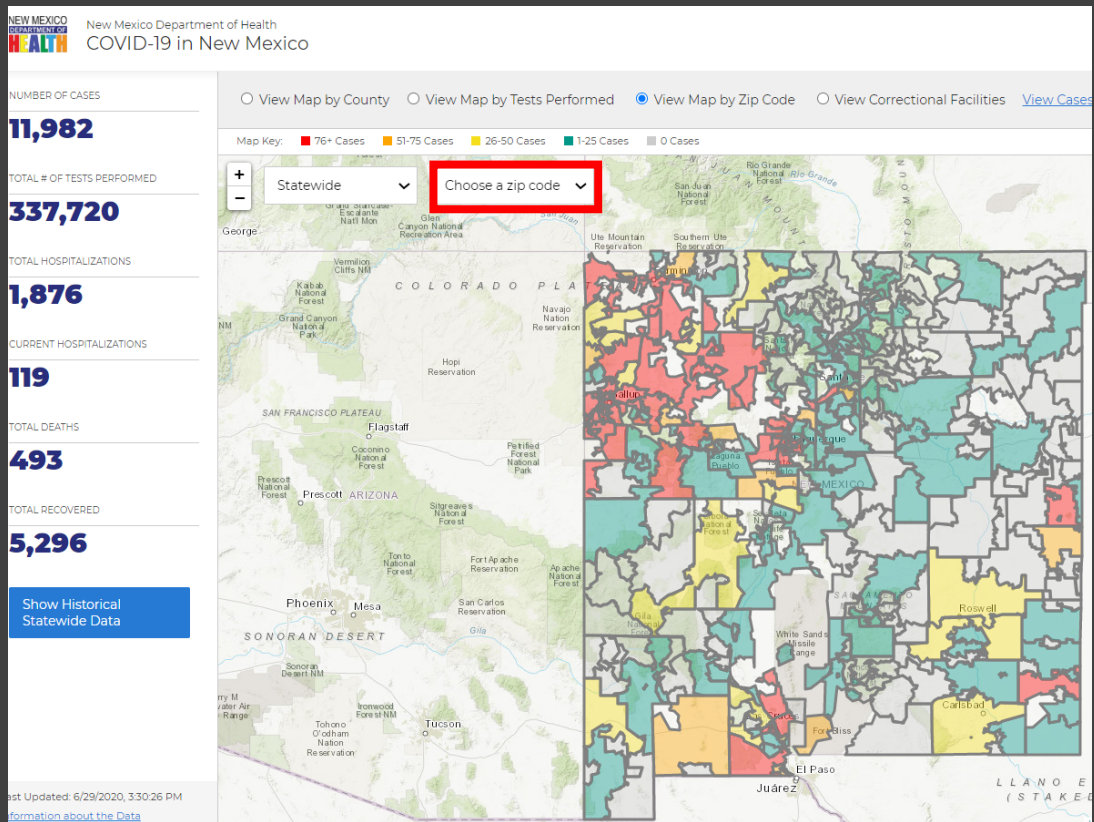
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DATA AND GOVERNANCE: THE INTERDEPENDENCE OF NATION REBUILDING AND DATA REBUILDING



Carroll, Stephanie Russo, Desi Rodriguez-Lonebear, Andrew Martinez. "Indigenous Data Governance: Strategies from United States Native Nations." Data and Governance: The Interdependence of Nation Rebuilding and Data Rebuilding. *Data Science Journal* 18(1)p.31. DOI: [10.5334/dsj-2019-031](https://doi.org/10.5334/dsj-2019-031).

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Public COVID-19 Data Dashboards: Two States, Two Approaches

The COVID-19 Current Reality When Tribal Data Sovereignty is Not Protected

Stigma and discrimination are being experienced by Native Americans

PROPUBLICA Graphics & Data Newsletters About

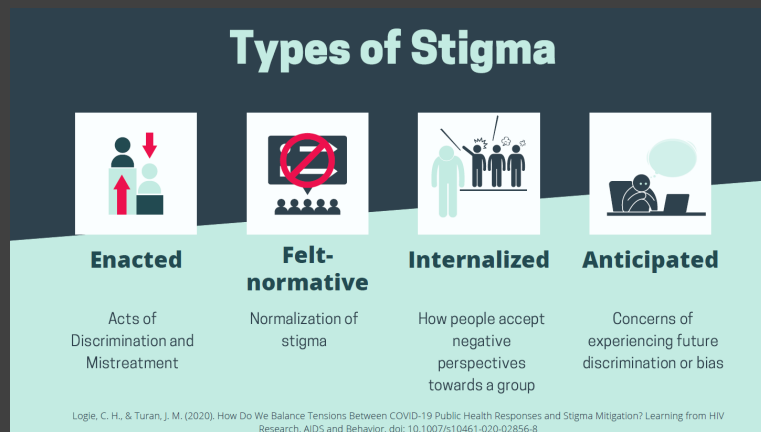
Health Care Trump Administration Criminal Justice Civil Rights More... Series Video

CORONAVIRUS

A Hospital's Secret Coronavirus Policy Separated Native American Mothers From Their Newborns

Pregnant Native American women were singled out for COVID-19 testing based on their race and ZIP code, clinicians say. While awaiting results, some mothers were separated from their newborns, depriving them of the immediate contact doctors recommend.

by Bryant Furlow, New Mexico In Depth, June 13, 5 a.m. EDT



Gallup on lockdown, State's Riot Control Act invoked

Local leaders say they're desperate to stop COVID-19 spread

583 Shares

Nancy Laflin Target 7 Reporter

Updated: 6:51 PM MDT May 1, 2020

UCLA AMERICAN INDIAN STUDIES CENTER

Coronavirus in Indian Country: Latest Case Counts

American Indian communities have some of the highest rates of coronavirus in the United States. However, this data is almost certainly incomplete as scholars have routinely shown how American Indian and Alaska Natives (and other Indigenous peoples as well) are often misidentified and undercounted in various administrative and vital statistics records. The charts below represent a joint effort by Indian Country Today, the American Indian Studies Center at UCLA, and the Ralph J. Bunche Center for African American Studies at UCLA to combat data invisibility.

About the Data

Data sourced from publicly available data collected by [Indian Country Today](#) to address data gaps regarding COVID-19 infections and deaths for American Indian reservations and Alaska Native villages.

Visualizations created as a research collaboration between the American Indian Studies Center at UCLA and the data team based at the Ralph J. Bunche Center for African American Studies at UCLA, working together to comprehensively document the disparate impact of the COVID-19 pandemic on Black, Indigenous, and other historically marginalized communities.

Data last updated on 6/15/20 for data through 6/5/20.

Case Rate by Tribal Nation

New Mexico In Depth

About Us NM COVID-19 Resource Page Money in Politics Education Criminal Justice

Report: Redistricting NM 2021 2019 Capital Outlay Allocations Subscribe Support Our Journalism

Don't Miss COVID-19 in New Mexico

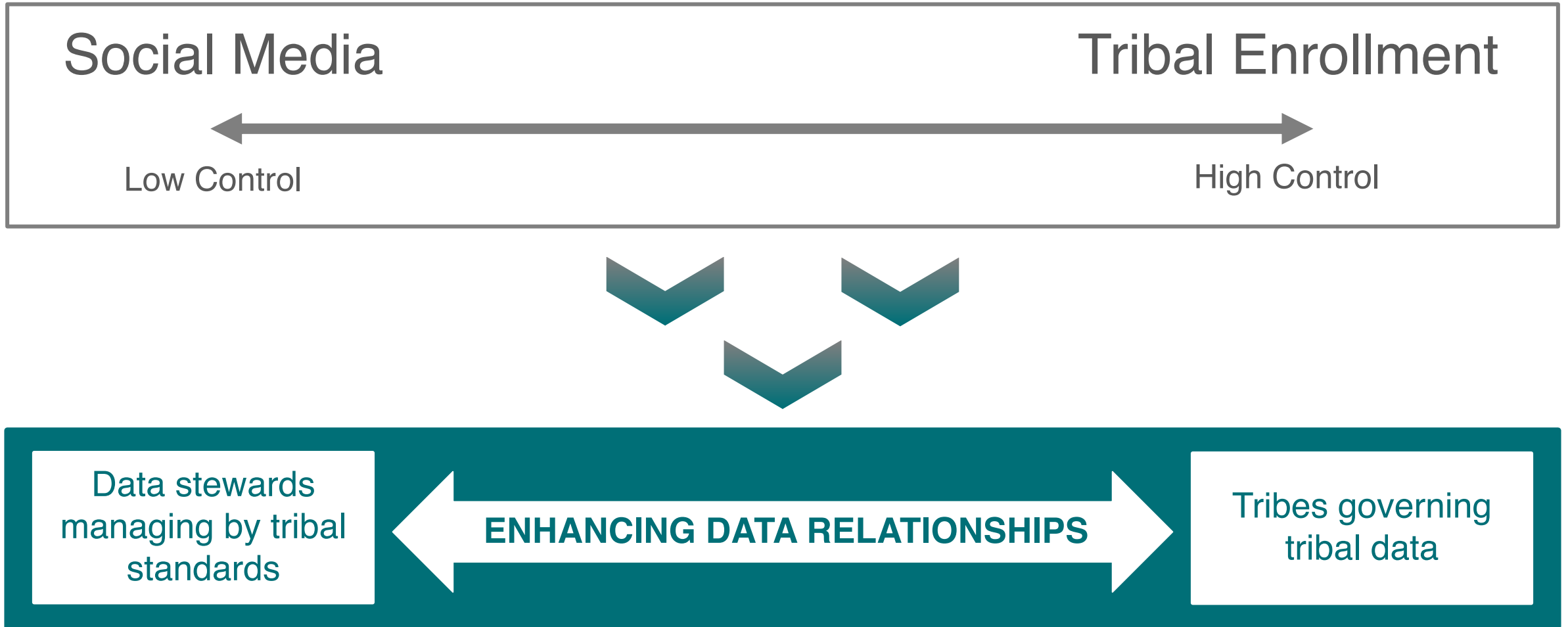
COVID-19 has spread to most New Mexico tribes

By Marjorie Childress, New Mexico In Depth | May 13, 2020

THE DATA PARADIGM: THE HIERARCHY OF INDIGENOUS DATA



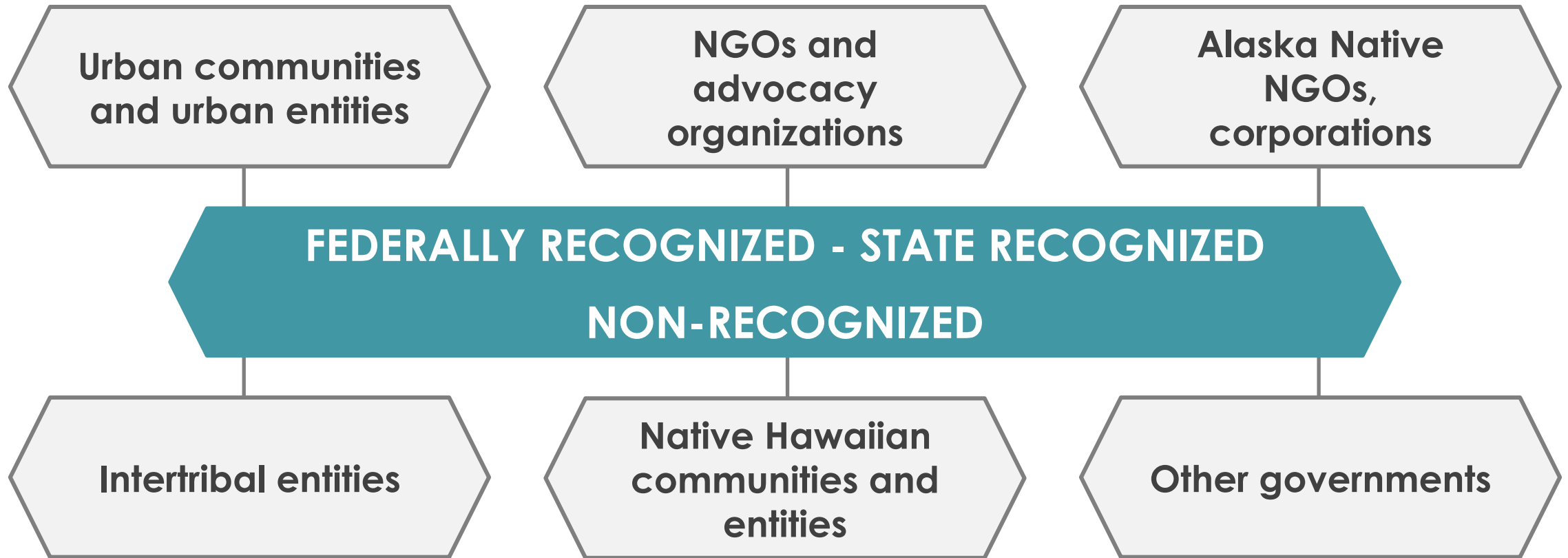
INDIGENOUS DATA GOVERNANCE



Rainie, S., and Jorgensen, M. DOI Tribal Data Meeting, July 2017, Flagstaff, AZ. Adapted from Kukutai, T. Indigenous Data Sovereignty and Governance Masterclass. Australian Indigenous Governance Institute. March 31 2017. Brisbane;

RIGHTSHOLDERS AND STAKEHOLDERS

INDIGENOUS DATA SOVEREIGNTY >> RELATIONSHIPS FOR INDIGENOUS DATA GOVERNANCE



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A COMMITMENT TO INDIGENOUS DATA SOVEREIGNTY SPANS THE GLOBE

NATION-STATE BASED, INDIGENOUS LED COMMUNITIES OF PRACTICE

- TE MANA RARAUNGA MAORI DATA SOVEREIGNTY NETWORK in Aotearoa/New Zealand temanararaunga.maori.nz
- UNITED STATES INDIGENOUS DATA SOVEREIGNTY NETWORK usindigenousdata.org
- MAIAM NAYRI WINGARA INDIGENOUS DATA SOVEREIGNTY COLLECTIVE in Australia miaimnayriwingara.org
- PACIFIKA INDIGENOUS DATA SOVEREIGNTY NETWORK in Aotearoa/New Zealand
- FIRST NATIONS INFORMATION GOVERNANCE CENTRE in Canada fnigc.ca
- NASCENT: SAMI/SÁPMI in Sweden, Mexico, Southeast Asia

INTERNATIONAL NETWORKS OF NETWORKS

- GIDA Global Indigenous Data Alliance gida-global.org
- Research Data Alliance hosted INTERNATIONAL INDIGENOUS DATA SOVEREIGNTY INTEREST GROUP <https://www.rd-alliance.org/groups/international-indigenous-data-sovereignty-ig>

Promoting Indigenous Control of Indigenous Data

- An International Network
- Advancing Indigenous Data Sovereignty and Governance
- Asserting Indigenous Peoples rights and interests in data
- Advocating for data for the self-determined wellbeing of Indigenous Peoples
- Reinforcing the rights to engage in decision-making in accordance with Indigenous values and collective interests

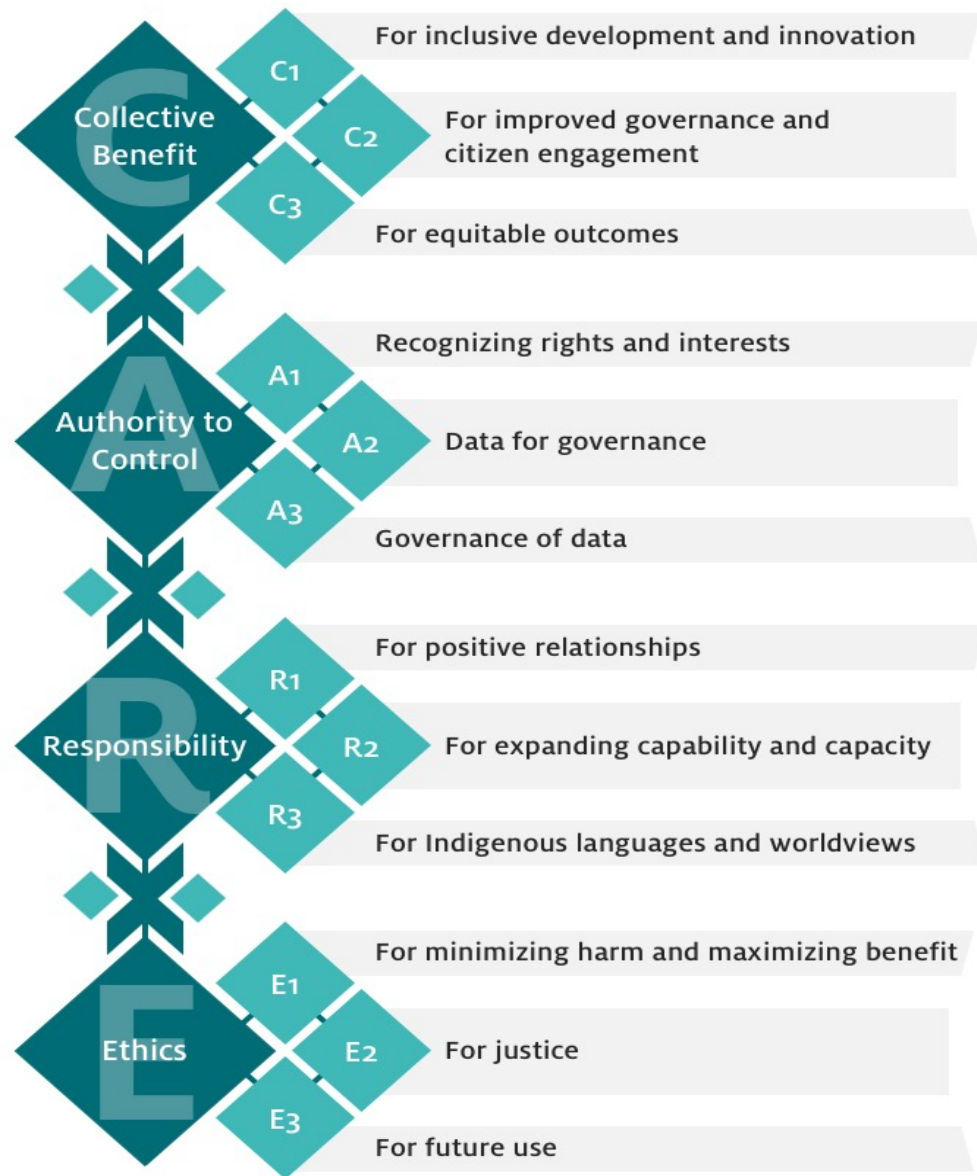


GIDA

Global Indigenous
Data Alliance

GIDA-GLOBAL.ORG | [@GidaGlobal](https://twitter.com/GidaGlobal)





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

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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.

Where can Indigenous Data Governance be put into practice?

- **Law**, e.g., Common Rule, UNDRIP, tribal
- **Policy**, e.g., government, institutional, org, professional guidelines
- **Ethics**, e.g., training, metadata labels
- **Infrastructures**, e.g., data standards, programming innovations



Policy Use Case: 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.

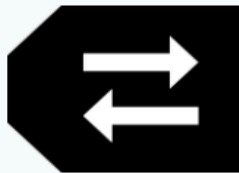
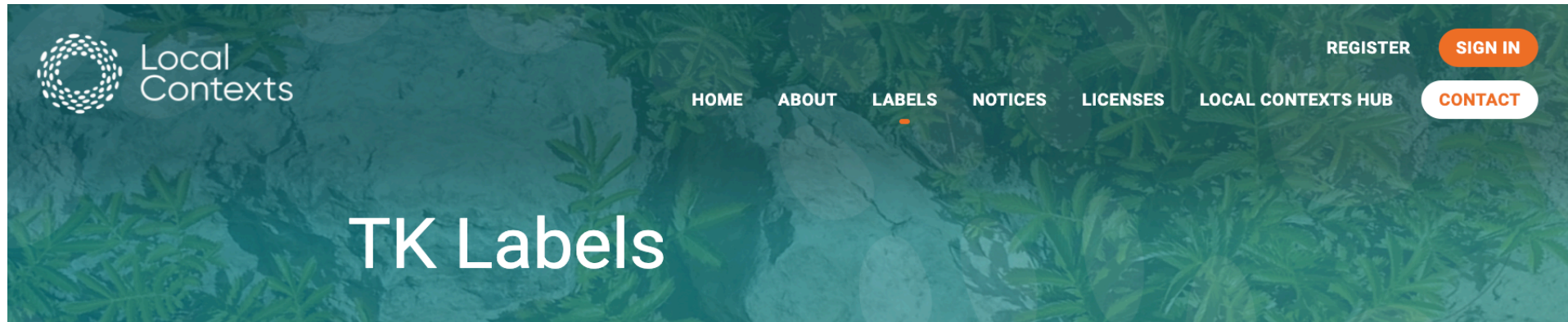
- a. ownership management and communication of research data and results should be negotiated between Indigenous peoples and the researcher or other parties based on the principles of Indigenous data sovereignty and governance.
- b. processes should be agreed at an early stage for ownership, management 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.⁶³

- a. where a conflict arises between accessibility and Indigenous peoples rights, then Indigenous peoples' rights should prevail.⁶⁴
- 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).⁶⁵

Practice Use Case: Traditional Knowledge Labels



TK Attribution
(TK A)



TK Clan
(TK CL)



TK Family
(TK F)



TK Multiple
Communities
(TK MC)



TK Outreach
(TK O)



TK Non-Verified
(TK NV)



TK Verified
(TK V)



TK Non-
Commercial
(TK NC)



TK Commercial
(TK C)



TK Culturally
Sensitive
(TK CS)



TK Community
Voice
(TK CV)



TK Community
Use Only
(TK CO)

Practice Use Case: Traditional Knowledge Labels



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AUDIO RECORDING

Passamaquoddy War song ; Trading song

Mihqelsuwakonutomon (Song of Remembrance in the Passamaquoddy War Song Series) ; Esunomawotultine (Trading dance/song) / Jesse Walter Fewkes collection of Passamaquoddy cylinder recordings SR29

About this Item

Title

Passamaquoddy War song ; Trading song

Other Title

Mihqelsuwakonutomon (Song of Remembrance in the Passamaquoddy War Song Series) ; Esunomawotultine (Trading dance/song)

Jesse Walter Fewkes collection of Passamaquoddy cylinder recordings SR29

Summary

The first song, Mihqelsuwakonutomon, means 'He/She tells memories of it'. This is a lament or mourning song. It is a fragment of one song in a series of songs and dances. Esunomawotultine, the trading dance, is the second song on Fewkes' wax cylinder 17 (Cylinder 4260; AFC 1972/003: SR29) recorded by Jesse Walter Fewkes in Calais, Maine, March 16, 1890.

Contributor Names

Fewkes, Jesse Walter, 1850-1930, recordist, speaker.

Selmore, Peter, performer.

Created / Published

1890-03-16.

Traditional Knowledge Labels



Attribution - Elihtasik (How it is done).



Outreach - Ekehkimkewey (Educational).



Non-Commercial - Ma yut monuwasiw (This is not sold).

[Learn more about the traditional knowledge labels](#)

Part of...

[American Folklife Center \(32,872\)](#)

[Library of Congress Online Catalog \(919,432\)](#)

Community-driven research generation: Gatherings



Supporting Tribal Data Governance for Community Climate Resilience in the Southwest



Community-driven research generation for Indigenous Data Governance

- Create capacity-building and leadership opportunities
- Intergenerational learning on the land
- Learn from current tribal law and policies
- Invest in community-driven policy development
- Inform institutional policies and practices

Staff: Andrew Martinez



Mary Beth Jäger



Indigenous Foods Knowledges Network

Network Charter

The inaugural meeting of the Indigenous Foods Knowledges Network (IFKN) was held on March 1-2, 2018 at the Gila River Indian Community (GRIC) in Arizona. The meeting was hosted by Althea Walker and colleagues from the GRIC Department of Environmental Quality and

POLICY BRIEF

Supporting Tribal Data Governance For Indigenous Community Climate Resilience

DOMINIQUE DAVID-CHAVEZ
DANIEL B. FERGUSON
ANDREW CURLEY



Strengthening Indigenous Governance

A Call to Action for Native Nations, Tribal Citizens, Governments, Organizations, Scholars, and Funders

POLICY BRIEF

Indigenous Data Sovereignty in Arizona: Setting an Agenda

STEPHANIE RUSSO CARROLL
ANDREW MARTINEZ



Strengthening Indigenous Governance

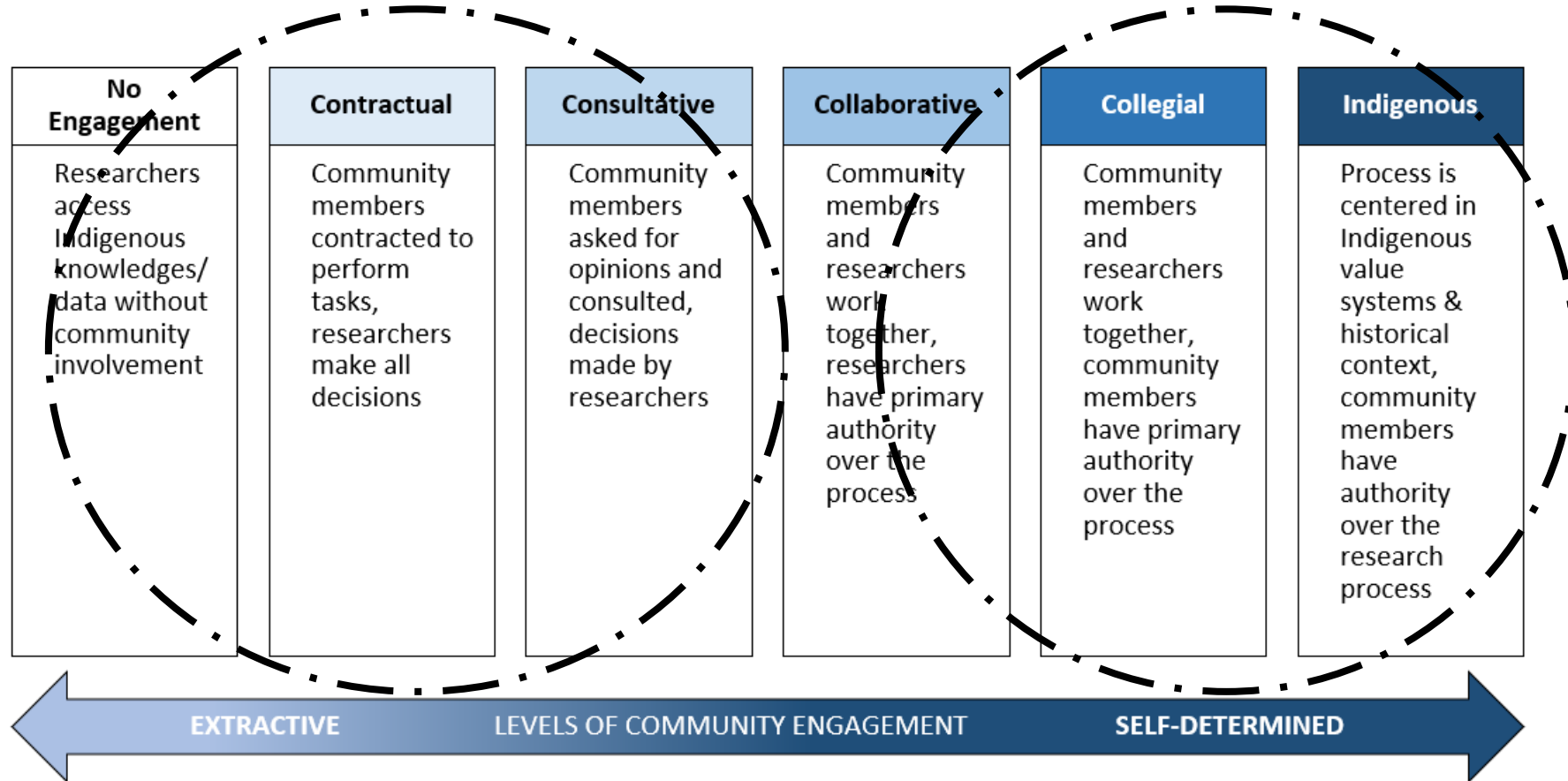
A Call to Action for Native Nations, Tribal Citizens, Governments, Organizations, Scholars, and Funders

Indigenous data sovereignty derives

Indigenous data sovereignty asserts rights of Native nation and Indigenous Peoples to govern the collection, ownership, and application of their own data.^{1,2} Indigenous data sovereignty derives from tribes' inherent right to govern their peoples, lands, and resources. In the United States and internationally, Indigenous data sovereignty has grown in recognition and action over the past five years.^{1,3,4,5} Defining a strategy for enhancing Indigenous data sovereignty for tribes in Arizona is needed in order to support tribal rights and interests in data.

Vast majority of climate studies (87%)

Indigenous research governance



(Adapted from David-Chavez & Gavin, 2018; Johnson, Lilja & Ashby, 2003; Biggs, 1989)

Analysis of Research Policies

Annual Review of Genomics and Human Genetics

Genomic Research Through an Indigenous Lens: Understanding the Expectations

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



Table 2. Comparison of Indigenous Research Guidelines

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

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

Analysis of Researcher Responsibilities

Rights, Interests, & Expectations: Indigenous Perspectives on Unrestricted Access to Genomic Data

Hudson et al. *Nature Genetic Reviews*. 2020.

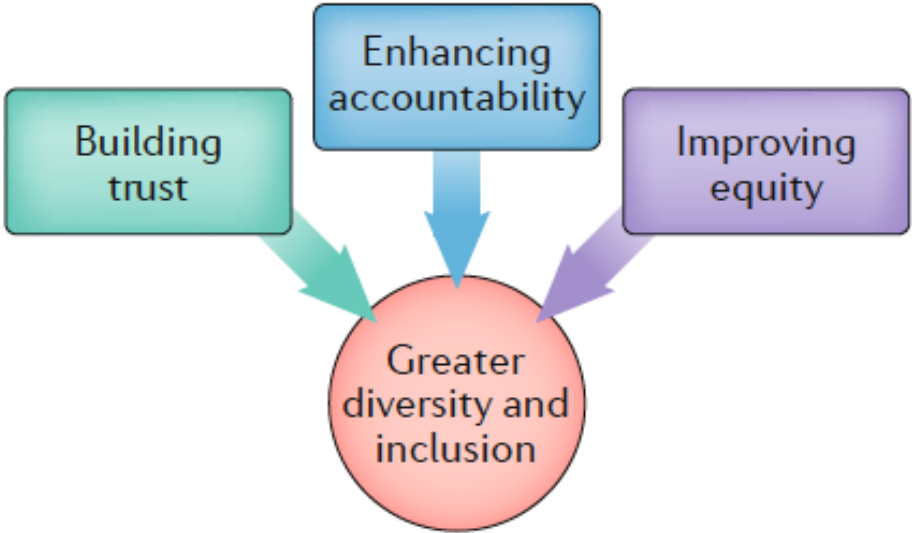


Table 1 | Enhancing responsiveness towards Indigenous rights and interests in genomic data

Principle	Issues raised by communities	Actions for researchers
Building trust	Lack of early consultation	Engage with the appropriate entity to discuss the aims of the project, including data use and access; engage community rights-holders/stakeholders about the use of cultural knowledge, customary laws and cultural protocols
	Plans for data access and secondary uses	Define informed consent language for potential data access and secondary uses; engage with Indigenous governance processes to establish a participatory governance process and decide secondary uses; provide community education and/or multilevel consent processes
	Receiving ongoing research updates	Communicate regularly via mechanisms determined by the community to enhance transparency
	Exercising data governance	Community determines the level of data access; abide by Indigenous governance processes that support control over samples and data
Enhancing accountability	Formalizing data access and secondary use agreements	Obtain tribal/board approval and develop a memorandum of understanding; secondary use process established with potential community veto
	Protecting personal identifiers	Maintain appropriate levels of privacy; develop mechanisms to remove a participant's data from data sets (for future uses)
	Protecting community identifiers	Consultation with Indigenous communities to reduce collective harms; create a publication review process that honours Indigenous considerations regarding results (how the community wants to be named) and interpretations (reduce bias), and develop mechanisms to remove a community's data from data sets (before analysis)
	Appropriate study design	Studies should be designed to ensure equal explanatory power (statistical significance for subpopulation analyses) and produce relevant results for Indigenous communities
	Preventing misuse of data	Where expertise is available, involve Indigenous scholars and community members in data analysis and interpretation; community involvement in data governance and decisions about data access
Improving equity	Improving publication standards	Recognize origin and provenance of samples, recognize community support for the study and recognize data availability and data governance processes
	Recognizing community rights and interests	Appropriate attribution of community support within publications
	Collecting appropriate cultural metadata	Work with communities to collect relevant traditional knowledge and community interests; use labels to maintain provenance on data-sharing platforms
	Formalizing benefit-sharing agreements	Develop formal agreements for benefit sharing or process to transition from research to commercial applications
	Enhancing capacity	Collaborate with communities to build capacity and capability in the data life cycle

Projects: Indigenous self-determination in US research governance



Table 1
Framework for understanding oversight in AI/AN communities

Tribal Nation	Tribal College	Tribally Based or Focused Organization/ Department	Indian Health Service (IHS)
Entity authorized to provide the ethical review and monitoring of research for one Tribal Nation or for a single reservation home to more than one Tribal Nation	Entity that provides the ethical review and monitoring of research for a Tribal College or University (TCU)*	Entity in an existing organization or department that provides the ethical review and monitoring of research for that organization or department and is within a Tribal Nation, and/or serving a Tribal Nation or Nations, and/or serving AI/AN peoples	An entity designated by IHS to provide the ethical review and monitoring of research conducted in IHS facilities within IHS regional or national designations

*Includes tribally and federally chartered colleges and universities. See the "Tribal College Research Oversight" section for further information.

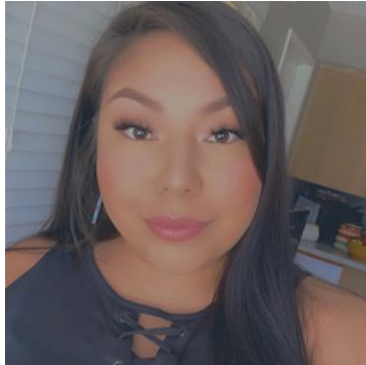
Around Him et al., *Am Indian Alsk Native Ment Health Res.* 2019;26(2):71-95

Project: Tribal Research Codes

Post Doc
Ibrahim Garba



MPH student
Danella Hall



US Tribal Research/IRB Codes

- 1) Jurisdiction
- 2) Engagement and Participation
- 3) Review
- 4) Costs
- 5) Appeals
- 6) Enforcement/Sanctions
- 7) Evaluation
- 8) Values, Culture, Tradition, Knowledge, Religion/Spirituality
- 9) Ownership and Control
- 10) Intellectual Property
- 11) Prepublication Review
- 12) Authorship and Acknowledgement
- 13) Commercial Applications and Financial Benefit

Theme: Jurisdiction n=15

Rights: Formal tribal approval is required regardless of external approvals (5/15)

Territory: Provisions apply on the territory/lands of the tribe (13/15)

Persons: Provisions apply to research with citizens/members based on affiliation/identification with tribe (12/15)

Navajo Nation which authorizes its IRB to review “human research which will occur within [its] territorial jurisdiction ... *or which otherwise concerns Navajo individuals as an identifiable group.*”

Similarly, the Pascua Yaqui Tribe’s code regulates research activity “on the Reservation or with *[T]ribal members.*”



Project: Ethical Indigenous Data Governance @Universities and @Federal Entities

1. What factors and indicators represent effective and ethically responsible research practice in Indigenous communities?
2. To what extent are these factors and indicators represented in codes of ethics and responsible research guidelines at U.S. federal agencies and Universities?



Research Framework:

1. Document Analysis

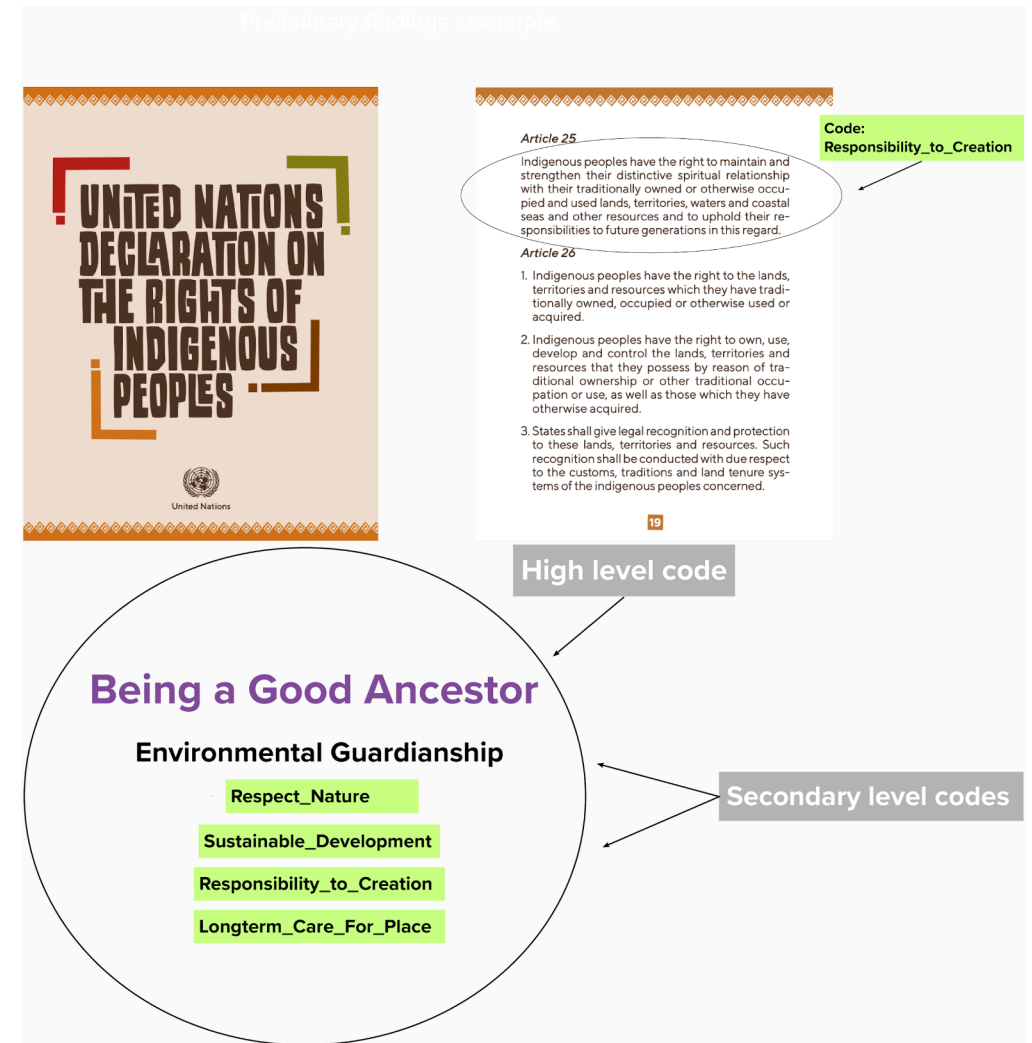
2. Institutional Analysis

3. Expert & Community Engagement

Panel I: tribal leaders/staff, Indigenous and allied scholars

Panel II: mainstream data, ethics, and policy leaders from across the country

4. Share Resources



- Cultural responsiveness
- Reciprocal relationships
- Honoring rights
- Ethics in balance
- Centering Indigenous governance
- Being a good ancestor

Why are these efforts important for ethical Indigenous Data Governance?

1. Informing new **standards**
2. Data to guide development of **resources and trainings**
3. **Capacity-building** at tribes and institutions
4. **Mentorship** for Indigenous scholars
5. **Strengthening** intertribal and cross-cultural collaborative **partnerships** at national levels
6. Informing research policy and data governance to **enhance accountability** and **improve equity**
7. Supporting reciprocity and **trust** between research institutions and Indigenous communities

The screenshot shows the IEEE SA website header with navigation links: IEEE.org, IEEE Xplore Digital Library, IEEE Standards, IEEE Spectrum, and More Sites. On the right, there are links for eTools and the IEEE logo. Below the header, a navigation bar includes Standards, Products & Services, Technologies & Initiatives, and Participate. A search bar with a magnifying glass icon is present, along with a 'MAC ADDRESS' button and a 'BUY STANDARDS' button. The main content area displays the title 'P2890 - Recommended Practice for Provenance of Indigenous Peoples' Data' in large, bold, white text on a dark background.

IEEE.org IEEE Xplore Digital Library IEEE Standards IEEE Spectrum More Sites eTools IEEE

IEEE SA Standards Products & Services Technologies & Initiatives Participate Search Q MAC ADDRESS BUY STANDARDS

P2890 - Recommended Practice for Provenance of Indigenous Peoples' Data

Operationalizing Indigenous Data Governance

- Leverage international norms: CARE and FAIR Principles, UNDRIP
 - Develop indicators for the implementation of the CARE Principles
 - Develop a strategy for bidirectional capacity enhancement and funding for infrastructure (hard and soft) to enhance trust, accountability, and equity
 - Co-produce policy and practice to embed rights, interests, and ethics
 - Promote alternative licensing and agreement systems that support communities in their engagement with external data systems
 - Create, expand, implement practical mechanisms within data infrastructures that embed provenance, protocol, and permissions
-

GOVERNING DATA

VALUES & PRINCIPLES



Institutions/
Decision Making
Structures



Policies and Procedures

MECHANISMS FOR GOVERNANCE

Legislation Guidelines

Partnerships

Cultural Protocols

MOAs/MOUs

Stewardship

Data Sharing Agreements

Metadata

Permissible Uses



Tips to Supporting Indigenous Data Sovereignty

Recognize and promote sovereignty.

Use and support existing tribal and Indigenous data governance protocols and procedures.

Conduct scholarship in service to community and community-driven research that builds capacity within communities.

Support Indigenous scholars, whether they are in communities or in the academy. Include them at the decision-making table, as co-authors, and as grant reviewers.

Center Indigenous values when working in Indigenous communities.

PRESENTATION OUTLINE

1. Introduction and Definitions
2. What are Indigenous Data?
3. Indigenous Data Sovereignty
4. Indigenous Data Governance
5. Initial Questions and Discussion
6. The CARE Principles for Indigenous Data Governance
7. Indigenous Data Sovereignty and Governance in Practice
8. Questions and Discussion

Indigenous Data Sovereignty: An Overview and Potential Application of Data Governance for CRITFC

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Inter-Tribal Monitoring Data Project Annual Meeting | April 13, 2021



[USINDIGENOUSDATA.ORG](https://usindigenousdata.org)
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Collaboratory for Indigenous Data Governance Research,
Policy, and Practice for
Indigenous Data Sovereignty

[INDIGENOUSDATA.ORG](https://indigenousdatalab.org)
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POLICY BRIEF

Indigenous Data Sovereignty in Arizona: Setting an Agenda

STEPHANIE RUSSO CARROLL
ANDREW MARTINEZ

Indigenous data sovereignty derives from tribes' inherent right to govern their peoples, lands, and resources. In the United States and internationally, Indigenous Data Sovereignty has grown in recognition and action over the past five years.



Strengthening Indigenous Governance

A Call to Action for Native Nations, Tribal Citizens, Governments, Organizations, Scholars, and Funders

Indigenous data sovereignty asserts the rights of Native nations and Indigenous Peoples to govern the collection, ownership, and application of their own data.^{1,2} Indigenous data sovereignty derives from tribes' inherent right to govern their peoples, lands, and resources. In the United States and internationally, Indigenous data sovereignty has grown in recognition and action over the past five years.^{1,3,4,5} Defining a strategy for enhancing Indigenous data sovereignty for tribes in Arizona is needed in order to support tribal rights and interests in data.

A Convening

On April 24, 2019, the "Indigenous Data Sovereignty Summit in Arizona: Building shared understanding and identifying Tribal Leader needs" was held at Arizona State University in Tempe, Arizona. Summit attendees included tribal leaders and data practitioners, academic researchers, employees of the state of Arizona that have experience working with Native nations, students, and others. The day included grounding presentations on Indigenous data sovereignty in practice and facilitated discussions. Summit presenters shared how the Indigenous data sovereignty framework applied to their research with their own tribal communities.

Summit Objectives

The Summit's goal was to gain an understanding of how to enhance and strengthen tribal data systems, data collection, data analysis, data capacity building, and workforce competency around data management and control for tribes in Arizona. The objectives were to:

- (1) Better understand Indigenous data sovereignty principles to build efficient data systems in Indian Country.
- (2) Identify practical implementation and evaluation strategies for tribal departments and community members.
- (3) Determine the role of tribal governance in developing Indigenous data sovereignty protocols and procedures.

1 | Carroll, S. R., Rodriguez-Lonebear, D., & Martinez, A. (2019). Indigenous Data Governance: Strategies from United States Native Nations. *Data Science Journal*, 18(1), 31. DOI: <http://doi.org/10.5334/dsj-2019-031>

2 | Kukutai, T. and Taylor, J. 2016. Data Sovereignty for Indigenous Peoples: Current Practice and Future Needs. In: Kukutai, T and Taylor, J (eds.), *Indigenous data sovereignty: Toward an agenda*, pp. 1–22. Canberra, Australia: Australian National University Press. DOI: <https://doi.org/10.22459/CAEPR38.11.2016.01>

3 | Rodriguez-Lonebear, D. 2016. Building a data revolution in Indian country. 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/CAEPR38.11.2016.14>

4 | National Congress of American Indians. 2018. Resolution KAN-18-011: Support of US Indigenous Data Sovereignty and Inclusion of Tribes in the Development of Tribal Data Governance Principles. 4 June 2018. Available at http://www.ncai.org/attachments/Resolution_gbuJbEHWpkOgcwCIFinal.pdf

5 | Kukutai, T., & Taylor, J. (Eds.). (2016). *Indigenous Data Sovereignty: Toward an agenda*. Acton ACT, Australia: ANU Press. Retrieved from <http://www.jstor.org/stable/j.ctt1q1crgf>

Enhancing Indigenous Data Sovereignty in Arizona

Attendees convened in three separate workgroups defined by their primary, self-selected work focus: tribal leaders and representatives; researchers and academics; and individuals that work with tribal communities in Arizona. The goal of the workgroups was to gain a deeper understanding of how the Indigenous data sovereignty framework is or might be applied in their work.

Tribal leaders

Tribal leaders identified a desire to govern both research and data to the benefit of the tribes.

The tribal leaders group highlighted the necessity of:

- Networking and building relationships with researchers and others engaging with data about and with tribal communities, including identifying what data are being collected and how data are used.
- Equipping researchers with the history of research in the community, community goals, and opportunities to enhance tribal data capacity and capability to strengthen tribal governance of research and data.
- Engaging in community-driven research that aligns with goals and needs, and enhances capacity and capability.
- Assessing the tribe's current data infrastructure and developing it further to protect and benefit the community.
- Implementing research and data policies (eg, data collection, data sharing, researcher agreements, research review boards) and making them publicly available.
- Creating internal tribal data infrastructure and policy to facilitate data sharing within tribes.
- Communicating with tribal citizens regarding these topics in order to design policy and research priorities that align with the future goals of the community.

Academics

The academic group discussed their responsibilities to the communities in which they work or collaborate.

The academic group highlighted the necessity of:

- Understanding tribal sovereignty, potential cultural impacts of the work, and history of research with the community.
- Asserting tribal rights to and interests in data; researchers are data stewards and do not own the data.
- Involving community members in the data processes to enhance capacity and capability.
- Disseminating and returning data, information, and lessons learned to the community.
- Communicating with tribal leaders and community members from beginning to end of the research as an act of responsible research.
- Actively collaborating with communities to guide the research process and information dissemination.
- Navigating research collaborations and building relationships takes time and looks different for every community. Tribal policies and procedures such as tribal IRBs, tribal codes, and other research review processes provide a guide.

Working with tribes

Those working with tribes emphasized the need for stronger relationships and increased engagement of tribes, including Indigenous project or research team members and seeking direct feedback from tribes on projects.

The entities working with tribes group highlighted the necessity of:

- Recognizing and supporting expertise in tribal communities.
- Assisting with survey development, sharing analysis methodology, and building and leveraging capacity for tribally-led data collection.
- Actively incorporating the Indigenous data sovereignty framework into discussions about working with tribal communities.

- Assessing internal policies that may hinder the development or implementation of the Indigenous data sovereignty framework.
- Working beyond mandated protocols to strengthen relationships with tribal communities for increased transparency and assist with enhancing capacity, capability, and infrastructure.
- Communicating with peers, coworkers, advisors, and leadership on why the Indigenous data sovereignty framework is necessary.
- Supporting tribal rights and interests in data, including tribal data ownership and control.

Recommendations for Supporting Indigenous Data Sovereignty in Arizona

- Future gatherings to educate and raise awareness of Indigenous data sovereignty for tribal leaders, tribal citizens, and youth.
- Convene focused events on specific issue areas such as climate, human health, and intellectual property law.
- Share tribal research and data governance policies and regulations, as well as learning about what other tribes have done.
- Create institutional policies and guidelines in support of Indigenous data sovereignty and tribal research and data governance policies and regulations.
- Review of the Arizona Board of Regents Tribal Consultation Policy and its implementation at the three state universities.
- Educate researchers and those working with tribal communities on tribal sovereignty and the history of problematic research in Arizona.
- Provide technical assistance and funding for tribal communities to develop Indigenous data governance protocols and procedures.

This brief was produced by the Native Nations Institute and the Inter Tribal Council of Arizona with funding support from the Morris K. Udall and Stewart L. Udall Foundation, and has been made available to the US Indigenous Data Sovereignty Network.

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Questions?

For more information, contact the Native Nations Institute at **nni@email.arizona.edu**.

Join the Network!

For more information on the US Indigenous Data Sovereignty Network and to join its community of practice that supports Indigenous data sovereignty through data governance-focused research, policy advocacy, and education, visit **usindigenousandata.org** and join us on Twitter: @USIDSN.

Suggested Citation

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