
N CREW - Native Collective Research Effort to Enhance Wellness

Collective Learning Virtual Series:

RESEARCH AND OPERATIONS

**Indigenous Data Governance & Research:
Agreements, Policies, Codes**

with Christina Ore and Crystal Greensky

April 15, 2025

OVERVIEW

Welcome!

Introductions

Indigenous Data Sovereignty & Governance

Tribal Research Process: When to start discussions?

Data Sharing Agreements, Policies, & Codes

Closing



Intentions

Future generations of Indigenous youth will look at this time and see evidence of our traditional teachings embedded in our response: an honoring of the slowness, grief, and renewal; cherishing the well-being of our youth and Elders; a return to the land; and, above all, a communal responsibility to the collective well-being. (Brant-Birioukov 2021)

“Fundamentally, it’s about the inherent sovereignty that Indigenous peoples have.”
- Dr. Stephanie Russo Carroll



Indigenous Data Sovereignty & Governance

- Indigenous data
- Responsibilities
- Rightsholders
- Building relationships of trust



Illustration by Mario Valencia (Yoeme), 2024

Accessed 4.14.25

<https://www.sciencefriday.com/segments/indigenous-data-sovereignty/>



Indigenous Data Governance



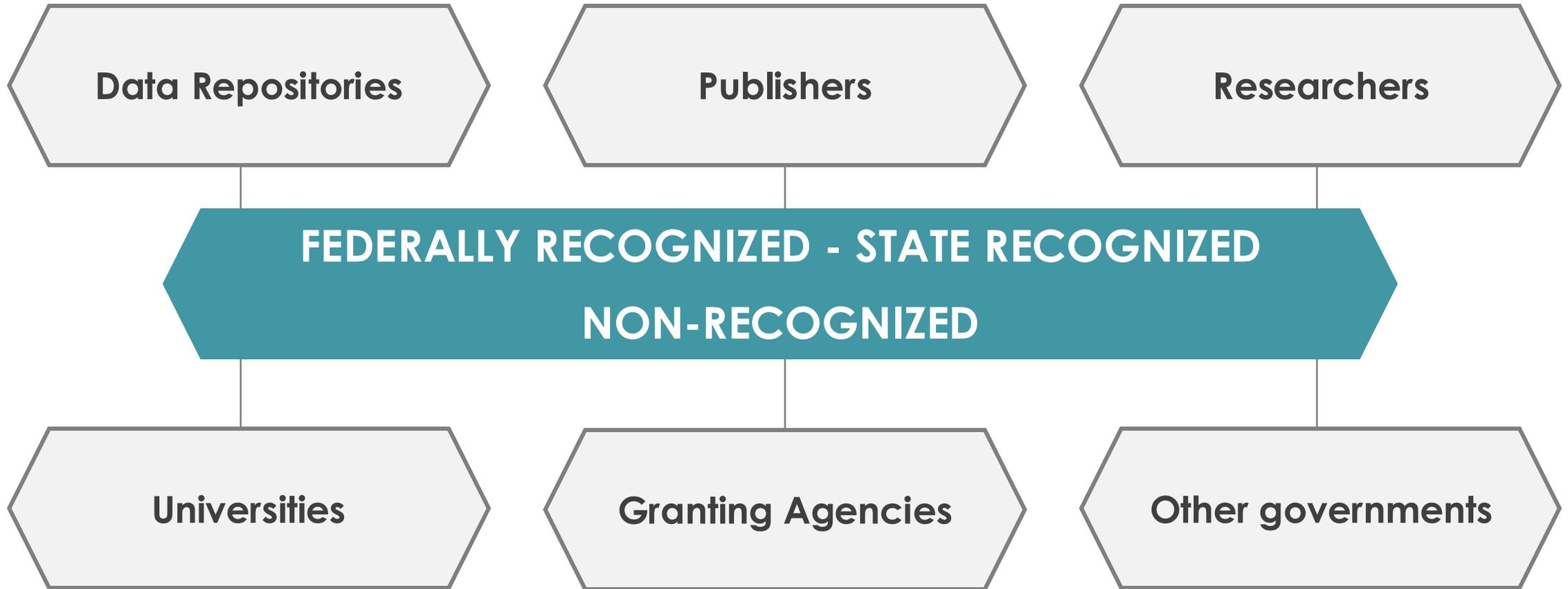
Carroll, S.R., Rodriguez-Lonebear, D. and Martinez, A., 2019. Indigenous Data Governance: Strategies from United States Native Nations. *Data Science Journal*, 18(1), p.31. DOI: <http://doi.org/10.5334/dsj-2019-031>

Data stewards
managing by tribal
standards

← **ENHANCING DATA RELATIONSHIPS** →

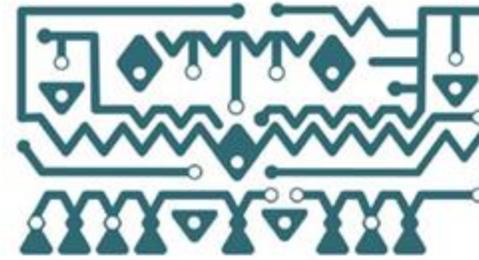
Tribes governing
tribal data

RIGHTSHOLDERS AND OTHER DATA ACTORS



IDGOV PRINCIPLES

BROAD PRINCIPLES



CARE Principles
for Indigenous
Data Governance

REGIONAL PRINCIPLES



Principles of
Māori Data
Sovereignty

Brief #1 | October 2018

This Te Mana Raraunga (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 data¹, 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"

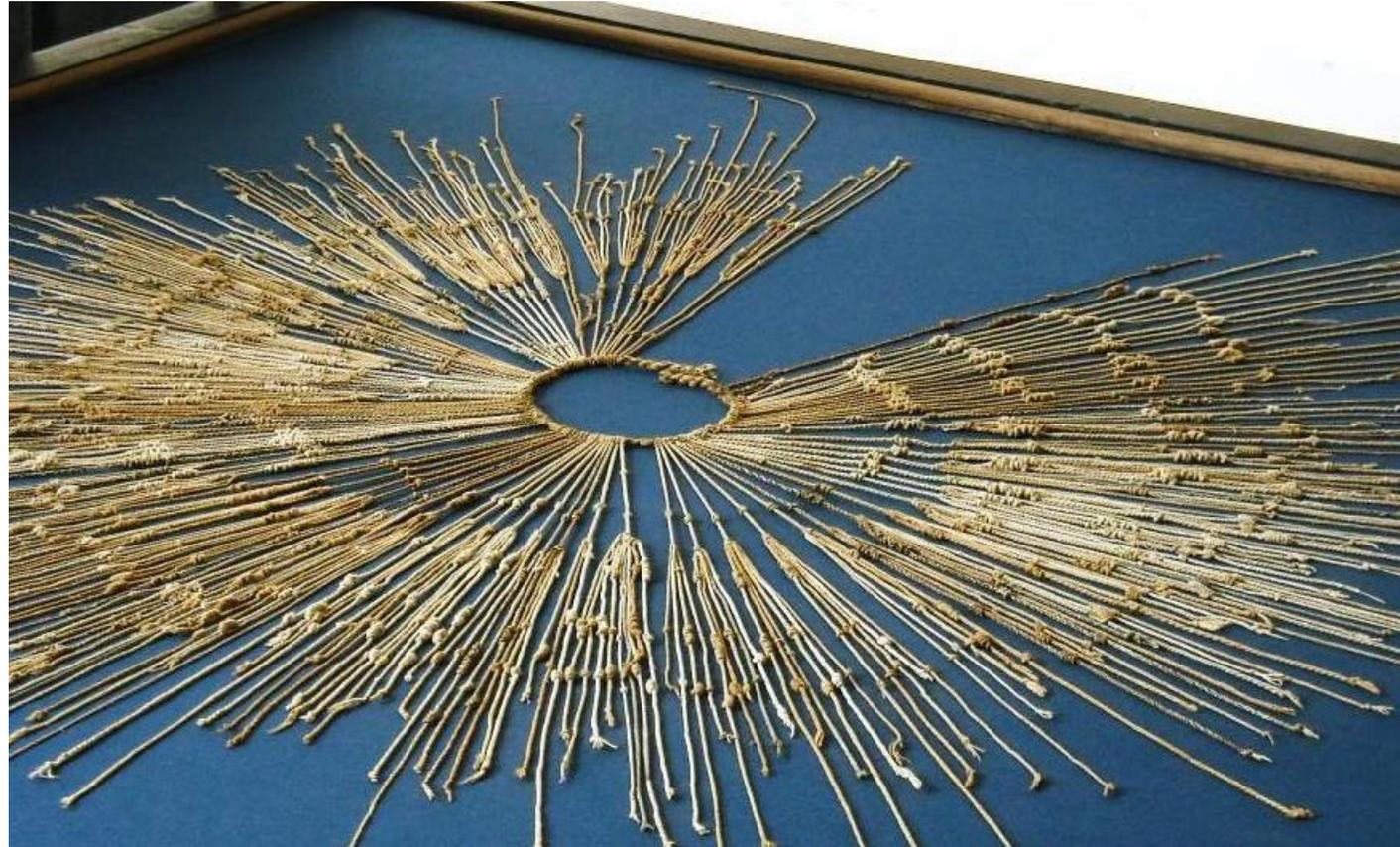
"One must have the right principles for important endeavours."

INDIGENOUS NATION

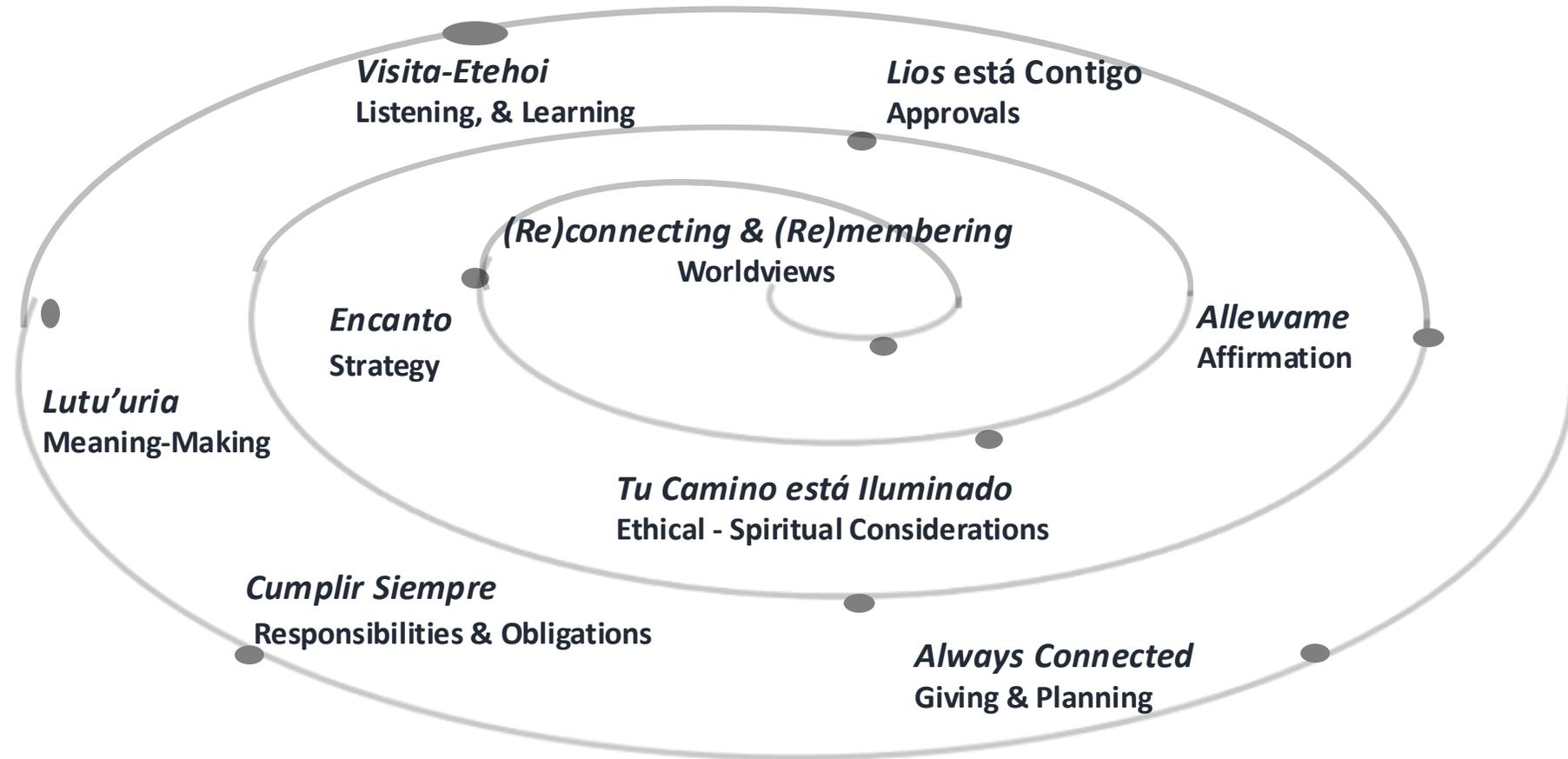
Governance, Policy & Protocol

Indigenous data sovereignty & governance

**OUR PEOPLES HAVE
ALWAYS BEEN DATA
EXPERTS**



Relational Indigenous-Centered Methodologies



Aligning systems, research ethics, and data stewardship
Agreements, Codes, Laws > Data Management Plan

Applying the Six R's to the Data Governance Process

- **Relationship:** Requires attention and effort to build and maintain – think of relationship as our kinship obligation.
- **Respect:** Recognition of a community's cultural standards and openness to learning.
- **Responsibility:** The all-inclusive process, recognizing our connections to Indigenous communities and our desire to continually develop sustainable, supportive relationships.
- **Representation:** Allows the community to identify what is relevant.
- **Relevance:** Valuing Indigenous knowledge, involving Indigenous communities, and ensuring that data governance plans for Indigenous peoples are responsive to the needs the community has identified.
- **Reciprocity:** Respectful knowledge sharing between investigator(s) and community, throughout the full research process.
 - Data governance is not a "one and done" task (akin to the consent process)

Tribal Research Process

- Assurance for Indigenous data governance built into tribal IRB process
 - When to start the data governance discussion? Straightaway!
 - Historically data sharing was after thought and investigator owned the data
- Standardized researcher & data sharing agreements
 - Exists in tantum with protocol
- Stalls when researcher not taking into consideration the principles of IDSov/IDGov

DATA SHARING AGREEMENTS N CREW



2025

Northwest Indian College

Northwest Indian College (Xwlemi Elh>Tal>Nexw Squal[3]) is a public tribal land- grant community college in Bellingham, Washington, United States. It was established by the Lummi Nation and is the only accredited tribal college or university serving reservation communities of Washington, Oregon, and Idaho.

Papa Ola Lōkahi

Founded in 1988, Papa Ola Lokahi is a 501(c)(3) that embodies the holistic approach that brings together mind, body and spirit in the pursuit of optimum health and well-being for Native Hawaiians.

CIRCLE P50

The Johns Hopkins Center for Indigenous Health, along with various Tribal and Urban Native collaborators, received a five-year, \$12 million P50 Center of Excellence award from the National Institutes of Health's National Institute on Drug Abuse under Award Number P50DA058619 to study and create resources for addressing problematic substance use and amplifying existing protective factors in American Indian and Alaska Native (AI/AN) communities.

DATA SHARING AGREEMENTS N CREW



2025

John Hopkins Center for Indigenous Health Circle P50

For the
<Protocol Title>
between the
<Tribal Nation Legal Name>
and
<Institution or Researcher [Institution]>

1. Project Purpose and Scope

- 1.1 **Project Purpose:** **<Tribal Nation Legal Name>** and **<Institution or Researcher>** are collaborating to plan, develop, and implement a research study about **<topic of research>** within the **<Tribal Nation Legal Name>** or properties owned by **<Tribal Nation >**.
- 1.2 **Principal Investigator(s):** The Lead Principal Investigator for this research is **<Researcher Name>**. The Co-PI's for this research are: **<Co-PI Name(s)>**.
Title and ID: The title for this research is: **<Protocol Title>** with **<Tribal Nation IRB>** - assigned ID# **<IRBID>**.
- 1.3 **Project Scope:** The research project, named **<protocol title>**, with IRB ID# **<Tribal Nation IRB ID>**, is **<brief description of project including sample size, eligibility criteria, and measures>**. This project shall be conducted in accordance with **<applicable Tribal Code #, Tribal Resolution #, Tribal Policy and Procedure>**, and 45 C.F.R. 46 et al., along with any and all other applicable federal standards governing research on human subjects.
- 1.4 **Project Period:** This Agreement will be in effect from the date of signature until up to **<end date>**, or until terminated in writing by either organization.
- 1.5 _____

First tribal data sharing agreement signed between the Tulalip Tribes and the Washington Dept of Health

We are Tulalip



“It’s a clear outline that tribes own their data in partnership with the state, because the state’s the one that’s collecting it.

But we want to tell our story, and we want to be able to work with DOH [department of health] to be mindful of our stories and to also get better access to the statistics.”

- Summer Hammons, Legislative Policy Analyst for Treaty Rights & Govt. Affairs Office at The Tulalip Tribes

<https://www.tulaliptribes-nsn.gov/> Accessed 4.14.25

<https://www.tulalipnews.com/2025/01/22/> Accessed 4.7.25

Codes, Laws & Policies

- Tribal Research codes may or may not include data codes
- Tribal Data codes
- Office of Indigenous/Tribal data governance

Conversation: Data Code

- What type of organizations are you developing data sharing agreements with for research?
- Are these agreements also internal with other programs/services?
- Have you had conversations with tribal leadership about developing an Indigenous data code?
 - Standardizing tribal data governance across all programs and services

UPCOMING WEBINAR

Te Pā Tūwatawata – Sovereign Data Storage for Indigenous Peoples

 **Thursday, April 17, 2025; 2pm PST/AZ**

Join us for a discussion on a distributed storage network that Māori have designed in Aotearoa New Zealand to empower their tribal nations and communities to collect, store, protect, access, and control their own data. This world-first data storage infrastructure called Te Pā Tūwatawata is led by the Te Kāhui Raraunga Charitable Trust (TKR), which aims to create a unique data storage system that promotes sovereignty over data and digital futures. Esteemed Māori data sovereignty leaders and advocates from TKR will showcase this groundbreaking data storage solution developed by Māori tribes for Māori tribes. Partnership opportunities for Indigenous Peoples in the United States will be discussed.



Ms Kirikowhai Mikaere
(Te Arawa - Tūhourangi, Ngāti Whakaue)
Lead Technician for the Data ILG and Te Kāhui Raraunga; leading Māori data and information specialist focused on harnessing information to empower indigenous community development



Erena Mikaere
(Tūhourangi, Ngāti Whakaue)
Founder of Waihuia Group, co-founder of software companies Identity Connection Evolution, and Indigenous Data Flow; leads a team of Māori engineers to serve tribal aspirations in data & digital sovereignty for Te Kāhui Raraunga.



Mr Christopher Cormack
(Kāi Tahu, Kāti Māmoe, Waitaha)
Kaihuawaere Mathiko at Catalyst IT. 28+ years experience in open source software; led development of the Koha library system; focuses on Māori data sovereignty, advocating for ethical data governance through his work with Te Kāhui Raraunga.

Who Should Attend?

Leaders, staff, and delegates (e.g., contractors), of Tribal Nations and Indigenous Peoples in the US; the island territories; Hawaii; Alaska nonprofits; and Alaska Native Corporations

Leaders may delegate staff or others to attend on their behalf



Scan the QR code or
use the link below to
register!

<https://zoom.us/meeting/register/sBA4vJCXQ1WlqQRaNYqcMg#/registration>



Co-Hosted by:

US Indigenous Data Sovereignty Network, Indigenous Data Exchange, Collaboratory for Indigenous Data Governance, Equity for Indigenous Research and Innovation Coordinating Hub, Data Warriors Lab, NBDC, Indigenous Land and Data Stewards Lab, and IndigeLab Network.

Next Steps: Tribal Data Storage & Repositories

This week

Tribal Data Storage & Information

- This world-first data storage infrastructure called Te Pā Tūwatawata is led by the Te Kāhui Raraunga Charitable Trust (TKR), which aims to create a unique data storage system that promotes sovereignty over data and digital futures.

 **Thursday, April 17th** at 11am HI / 1pm AK / 2pm PT / 3pm MT / 4pm CT / 5pm ET

<https://zoom.us/meeting/register/sBA4vJCXQ1WlqQRaNYqcMg#/registration>

Upcoming

Data Sharing Agreements Inventory and Guide

- Date TBC

The April webinars are a collaborative effort involving the [US Indigenous Data Sovereignty Network](#), the [Indigenous Data Exchange](#), the [Collaboratory for Indigenous Data Governance](#), the [Equity for Indigenous Research and Innovation Coordinating Hub](#) (ENRICH), the [Data Warriors Lab](#), the [Native Biodata Consortium](#), the [Indigenous Land and Data Stewards Lab](#), and the [IndigeLab Network](#).

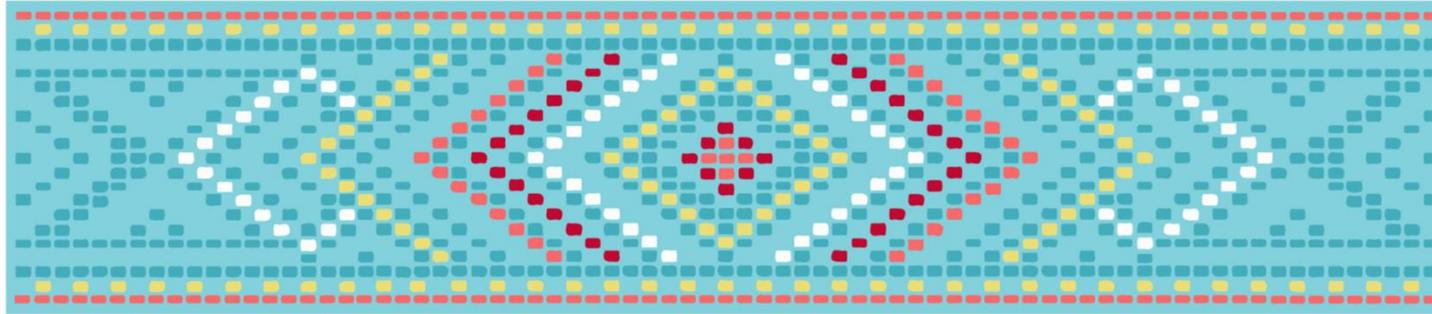
NCREW Collective Learning Virtual Series Announcements:

Data Governance Office Hours

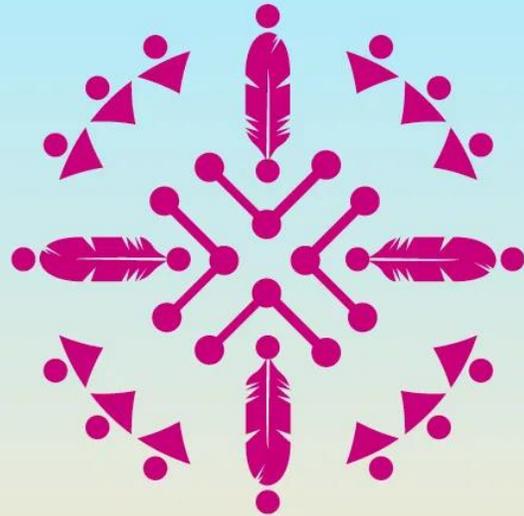
Join Elizabeth D'Amico and Carrie Johnson from PAWNIK

April 18, 2025 (Friday)

10 – 11 am PT/ 11 – 12 pm MT/ 11 – 1 pm CT/ 1 – 2 pm ET



UNITED STATES INDIGENOUS DATA SOVEREIGNTY NETWORK



SAVE THE DATE

**APRIL
14-17**

**2026
TUCSON**

**U.S. INDIGENOUS DATA SOVEREIGNTY
& GOVERNANCE SUMMIT 2026**

**Indigenous Data Sovereignty
MASTER CLASS**

04.14.26

**Student
PRE-CONFERENCE & LUNCHEON**

04.15.26

**Tribal Leaders
PRE-CONFERENCE & LUNCHEON**

04.15.26

-PLUS-

*Professional Development &
Certification Opportunities*

<https://usindigenousdatanetwork.org/>

Acknowledgment

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Contact Information

Crystal Greensky

(Little Traverse Bay Bands of Odawa Indian)

Center for Indigenous Health

Johns Hopkins Bloomberg School of Public Health

Deputy Director

Great Lakes Hub

218-724-1665

cgreens7@jhu.edu

Christina E. Oré

(Andean, Huancavelica, Peru)

Seven Directions A Center for Indigenous Public Health

University of Washington

Associate Director –Assistant Professor

US Indigenous Data Sovereignty Network

Member

520-404-1345

core1@uw.edu

Tupananchiskama