US INDIGENOUS DATA SOVEREIGNTY NETWORK

GIDA
Global Indigenous
Data Alliance

ORCiD

Randall Akee
UCLA

Jane Anderson
NYU

Stephanie Russo Carroll
University of Arizona

Helena Cousijn
DataCite

Laure Haak
Red Barn Consulting

Maui Hudson
University of Waikato

Katharina Ruckstuhl
University of Otago

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.

USINDIGENOUSDATA.ORG | @USIDSN

THE UNIVERSITY OF ARIZONA
NATIVE NATIONS INSTITUTE
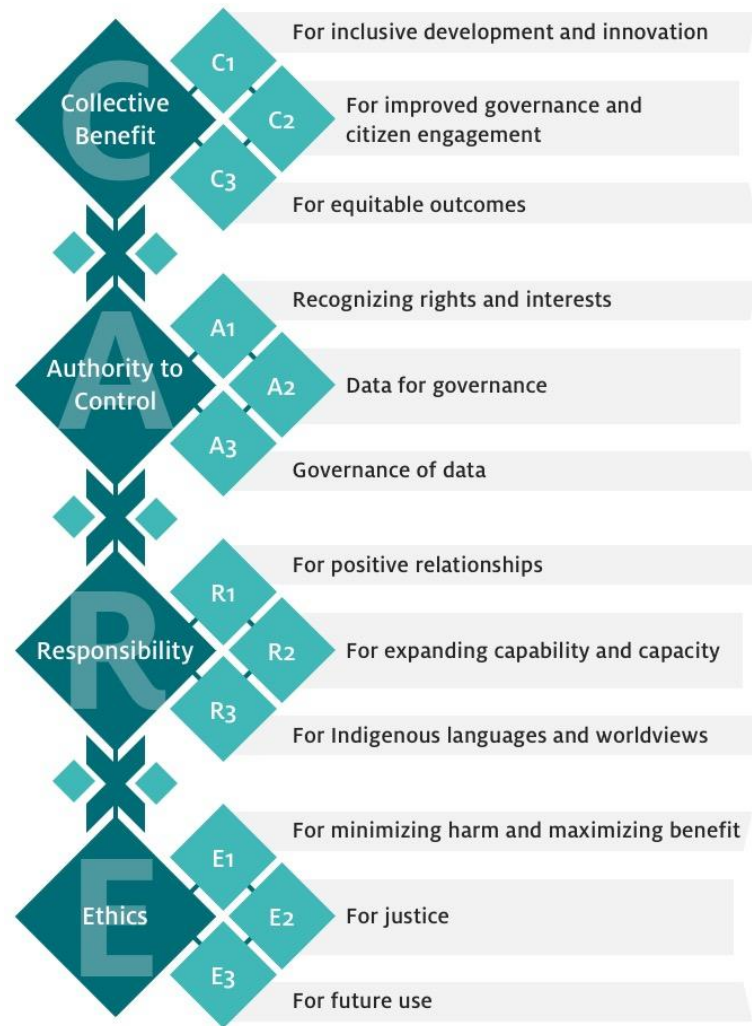Founded by the Udall Foundation
& the University of Arizona

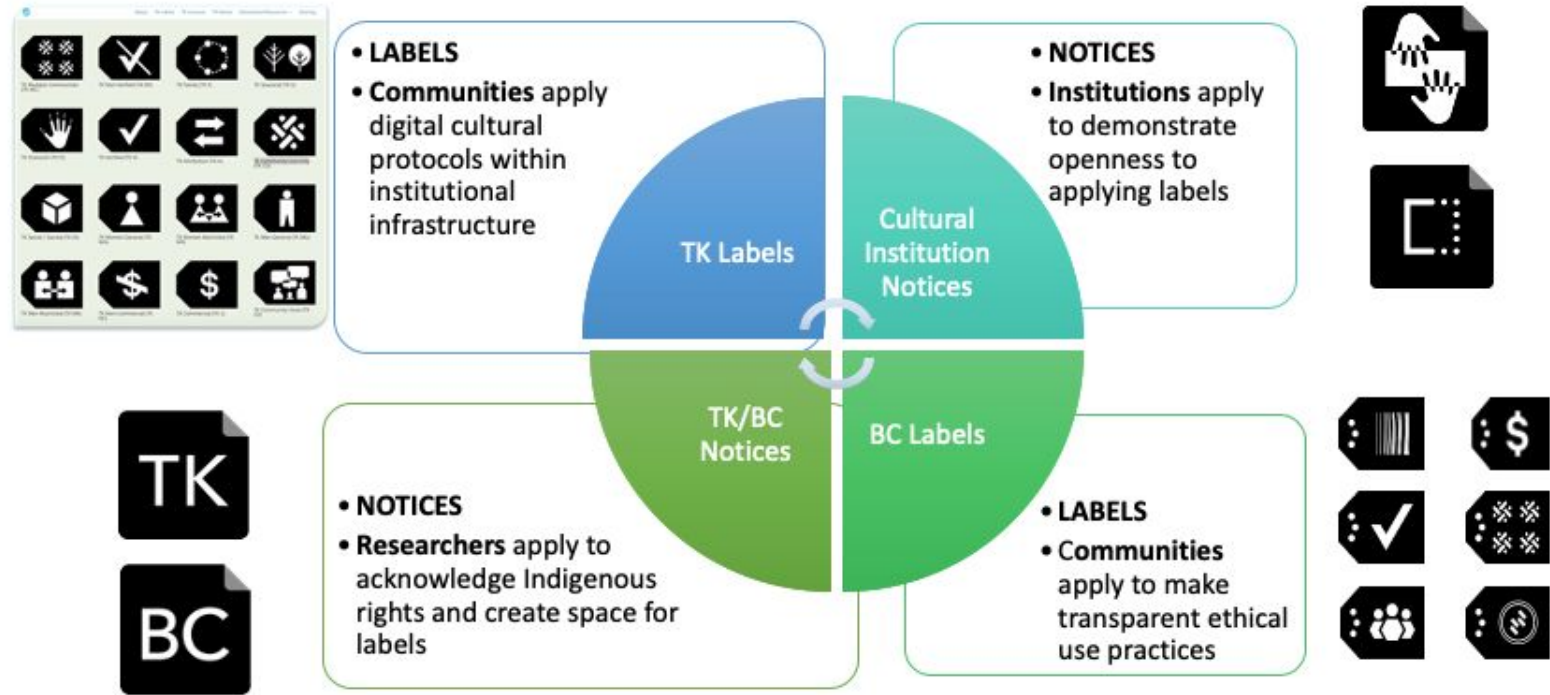*Strengthening Indigenous Governance*

CARE Principles for Indigenous Data Governance

www.gida-global.org/care

Carroll, Stephanie Russo, ..., Maui Hudson "CARE Principles for the Governance of Indigenous Data." Under review at *Data Science Journal*

Collective Benefit
C1 — For inclusive development and innovation
C2 — For improved governance and citizen engagement
C3 — For equitable outcomes

Authority to Control
A1 — Recognizing rights and interests
A2 — Data for governance
A3 — Governance of data

Responsibility
R1 — For positive relationships
R2 — For expanding capability and capacity
R3 — For Indigenous languages and worldviews

Ethics
E1 — For minimizing harm and maximizing benefit
E2 — For justice
E3 — For future use

Traditional Knowledge (TK) & Biocultural (BC) Labels +Notices

THE DATA LIFE CYCLE   Biocultural(BC)Labels

L.Liggins@massey.ac.nz
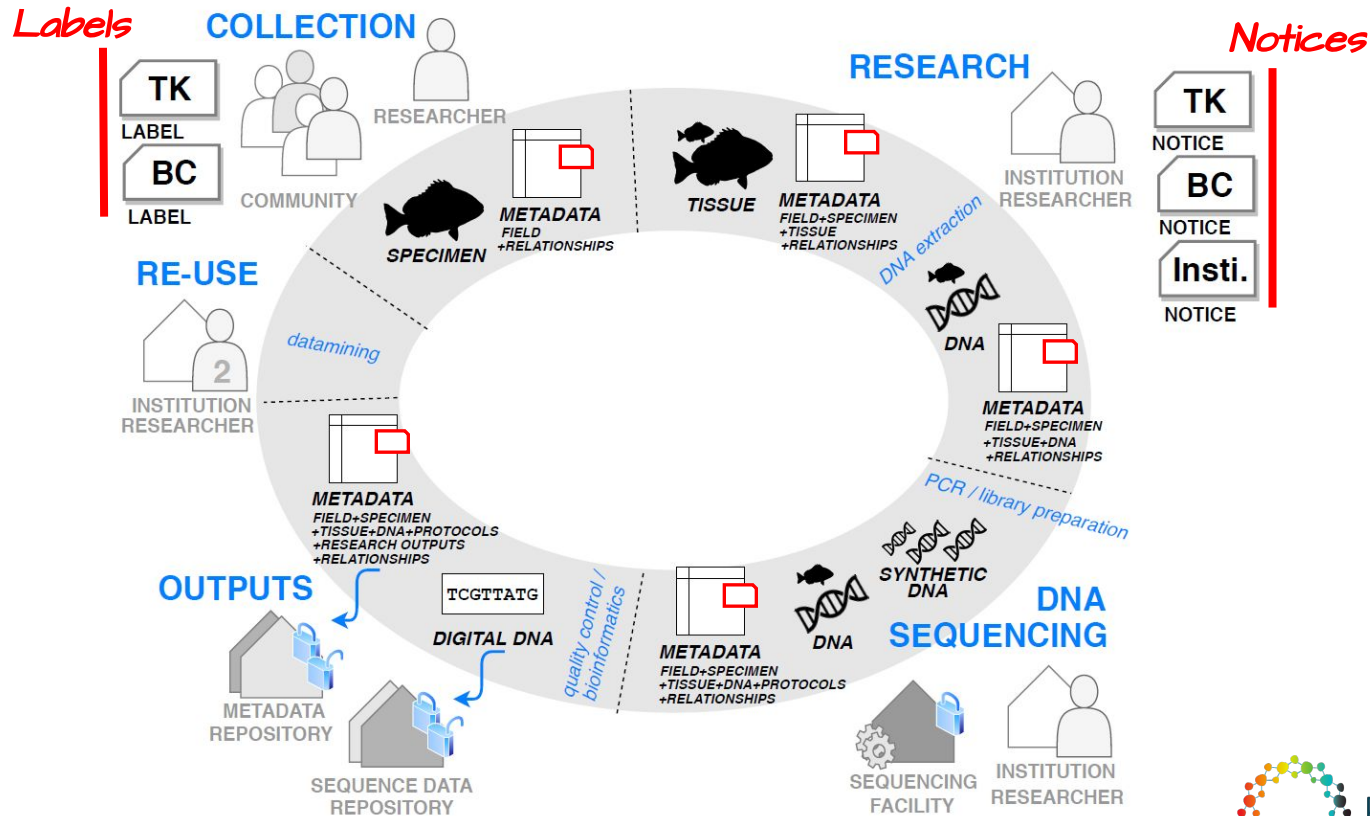
Christopher Chaney,

Senior Counsel for Law Enforcement and Information Sharing United States Department of Justice, Office of Tribal Justice.

Scientific Data and Indigenous Data Sovereignty

- **Scientific data:** the recorded factual material commonly accepted in the scientific community as necessary to validate and replicate research findings, regardless of whether the data are used to support scholarly publications

- **Indigenous Data Sovereignty:** the right of a nation to govern the collection, ownership, and application of its own data. It derives from tribes' inherent right to govern their peoples, lands, and resources

AI/AN Research Contexts: Focus on AI/AN

- Study designed to address questions for AI/AN
  - On tribal sovereign lands
    - single or small number of reservations
    - across a large number of reservations
  - Off tribal sovereign lands
    - Or combine reservation and off-reservation sites

AI/AN Research Contexts: General Population Research

- Not specifically focused on AI/AN but will draw into sample
  - Off Tribal Sovereign Lands
    - Further distinguish between studies that:
      - Collect tribal affiliation
      - Have a sample large enough to produce specific findings for AI/AN
  - On Tribal Sovereign Lands
    - Draw reservation into sampling frame
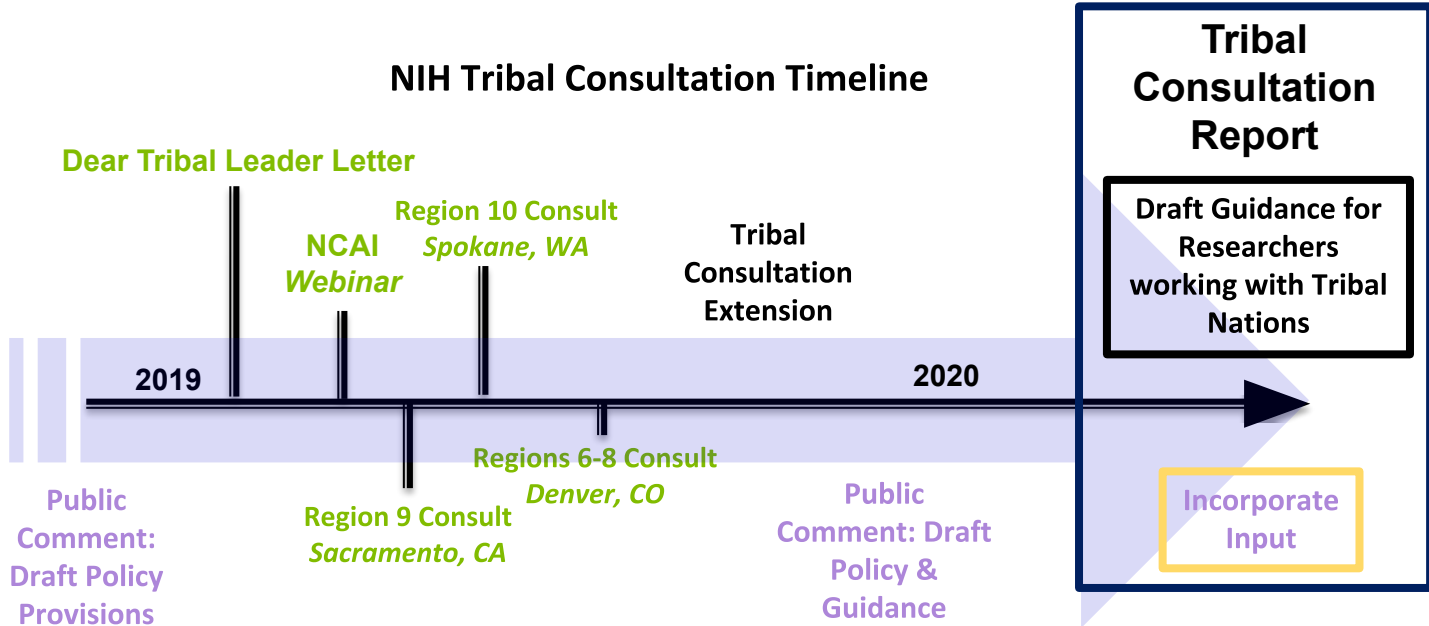
Tribal Policies and Practices for Research

- Predicated on Tribal Sovereignty

- Responsive to Past Research Abuses

- Differs from research conducted with other racial/ethnic groups

- Tribal Resolution Required

- Tribal IRB (if have IRB)

- Research with Tangible Health Benefits

- Community Engaged Research

- Community or Research Advisory Board

Examples NIH/HHS Policies or Guidance Relevant to IDS

- Common Rule (HHS Policy)

- Data management and Sharing Policy

- Single IRB

- Language contained in Funding Opportunity Announcements (FOAs)

NIH Tribal Consultation Timeline

Dear Tribal Leader Letter

NCAI
Webinar

Region 10 Consult
Spokane, WA

Tribal Consultation Extension

2019

2020

Public Comment: Draft Policy Provisions

Region 9 Consult
Sacramento, CA

Regions 6-8 Consult
Denver, CO

Public Comment: Draft Policy & Guidance

Tribal Consultation Report

Draft Guidance for Researchers working with Tribal Nations

Incorporate Input

Importance of Addressing Implementation of IDS: Why now?

- New Data Management and Sharing Policy being introduced where broad data sharing is *encouraged*
  - This can conflict with tribal policies or accepted processes

- All of Us Research Program has raised additional questions
  - Has or will likely draw in a large sample of AI/AN
    - Will have sensitive data
  - Tribes have expressed concern with engagement
    - Established Tribal Collaborative Engagement Advisory Group

When research is on tribal sovereign lands, the process and requirements are mostly clear…

And the principles of IDS apply across all contexts, however...

x

How is IDS implemented when off tribal lands and AI AN are from many tribes?

X

Will always defer to tribal law....

- But how is this implemented?
No clear process for obtaining research approval
  - Health and Community Centers do not have authority derived from sovereignty
  - Approval from each tribe?
    - Would be complicated and costly to implement, potentially introducing a barrier to participation in research
  - What about when tribal affiliation data are not collected?
    - Must be collected? Must be verified?
  - How proceed when laws, policies and infrastructure for research are at different stages – and are different - among tribes?

Other Questions

- Identification
  - Self-identification and/or verify tribal enrollment?
    - Mark data as self-identified?
- Who enforces tribal policies?
    - The NIH? Or tribes?
- How does the intersection of tribal authority and individual autonomy relate to research consent and sharing of data?

Support and Tools Needed

- Guidance document on AI AN research and data ownership/sharing

- Ethics statement for all public use datasets drawing attention to unique factors to consider for AI AN data?

- Trainings or courses on collection and use of AI AN data?
  - E.g., NCAI board game on research decisions

Support and Tools Needed

- Specific recommendations for when collecting data off tribal lands
  - When AI/AN are the focus
  - When a large number drawn into the sample
  - When a low number drawn into the sample
- Tribal listening sessions and consultations on how to proceed across studies

What does IDS and community engagement look like in each of these contexts?

Principles for AI AN research and AI AN Data use?

- Perhaps principles better than policies right now, because contexts vary significantly

- What principles should be included?
  - Protect and Benefit
  - Data in service to tribes and AI/AN people
  - Community Engagement
  - IDS Strategies

AMERICAN INDIAN AND ALASKA NATIVE RESEARCH IN THE HEALTH SCIENCES:

Critical Considerations for the Review of Research Applications

National Institutes of Health

Turning Discovery Into Health

Michael Pahn,

Head of Archives and Collections Digitization at the Smithsonian Institution's
National Museum of the American Indian Archive Center

Discussion, hosted by

Randall Akee
&
Maui Hudson