NATION BUILDING FOR WELLNESS:
TRIBAL DATA SOVEREIGNTY FOR HEALTHY INDIGENOUS COMMUNITIES

US INDIGENOUS DATA SOVEREIGNTY NETWORK
PRESENTERS

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Native Nations Institute and
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Partnerships for Native Health
Tribes, Native Nations, Indigenous Nations in the US are:

- Federally Recognized: 567
- State Recognized: 66
- Numerous Other Unrecognized
- Native Hawaiians
- Native Americans
OUR PEOPLES HAVE ALWAYS BEEN DATA EXPERTS

DATA SOVEREIGNTY → COLONIZATION → DATA DEPENDENCY

DECOLONIZING DATA

Rodríguez-Lonebear, D., (2016), Doctoral Research.
FROM SOVEREIGNTY TO DEPENDENCY

NON-WHITE BABIES NOW OUTNUMBER WHITE BABIES IN AMERICA FOR THE FIRST TIME.

SECOND.

DATA DEPENDENCY IN INDIAN COUNTRY

The paradox of scarcity & abundance

Inconsistency and irrelevance

Mistrust

External control – not by us, for us

Lack of data infrastructure and capability


INDIAN COUNTRY’S DATA STAKEHOLDERS

- Tribes: federally recognized, state recognized, non-recognized
- Urban communities and urban entities
- Alaska Native villages, tribes, corporations, NGO’s
- Intertribal relationships and entities
- NGO’s and advocacy organizations
## INDIAN COUNTRY’S DATA MAZE

<table>
<thead>
<tr>
<th>Data Source</th>
<th>Tribal Identifier</th>
</tr>
</thead>
<tbody>
<tr>
<td>U.S. Census</td>
<td>Self-identification</td>
</tr>
<tr>
<td>American Community Survey</td>
<td>Self-identification</td>
</tr>
<tr>
<td>Tribal Enrolment Data</td>
<td>Minimum blood quantum, lineal descent, and residency are the most common measures enforced by tribes.</td>
</tr>
<tr>
<td>Department of Housing and Urban Development</td>
<td>Census counts</td>
</tr>
<tr>
<td>Department of Education Scholarships</td>
<td>Tribal enrolment verification; Certificate Degree of Indian Blood from the Bureau of Indian Affairs</td>
</tr>
<tr>
<td>Bureau of Indian Affairs</td>
<td>A tribal service population is defined as all AIANs, citizens and non-citizens, living “on-or-near” a tribe’s reservation during the calendar year and who were eligible for BIA funded services.</td>
</tr>
<tr>
<td>Indian Health Service</td>
<td>Federally recognised tribal member living within the service area.</td>
</tr>
<tr>
<td>State and County Agencies</td>
<td>Census counts</td>
</tr>
<tr>
<td>Official Vital Statistics</td>
<td>Lack of data at the tribal level inhibits the ability to calculate vital statistics for enrolled tribal populations.</td>
</tr>
<tr>
<td>U.S. Armed Forces</td>
<td>Certificate Degree of Indian Blood from the Bureau of Indian Affairs</td>
</tr>
</tbody>
</table>

GOVERNANCE & 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. It is the way a society organizes itself to make and implement decisions.

**Government:**
An organization to do these things.

**Self-governance**

**Self-government**

**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.

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SOVEREIGNTY IS SELF RULE

As applied to Indigenous nations, sovereignty boils down to:
Who is going to decide...

• What constitution will the nation operate under?
• What environmental rules will govern?
• Should a natural resource get developed?
• Should a gaming casino be opened?
• What is taught in the reservation high school?
• What taxes are collected and from whom?
• Who can regulate and enforce contracts, provide remedies for negligent conduct, and adjudicate disputes over property?
• What data should be collected, where should it be stored, and how should it be used?
• Questions such as these?

Data sovereignty is the right of a nation to collect and manage its own data.
- Geographically bound; cloud
  (Rouse, 2013; http://whatis.techtarget.com/definition/data-sovereignty)

Data governance refers to the ownership, collection, control, analysis, and use of data.
(The Data Governance Institute, 2015; http://www.datagovernance.com/adg_data_governance_definition/)
INDIGENIZING DATA: DEPENDENCY → SOVEREIGNTY

INDIGENOUS DATA SOVEREIGNTY is the right of a nation to govern the collection, ownership, and application of its own data.

1. Derives from tribes’ inherent right to govern their peoples, lands, and resources.
3. Collective and individual rights.

INDIGENOUS DATA SOVEREIGNTY IS SUPPORTED BY INTERNATIONAL POLICY
UN DECLARATION ON THE RIGHTS OF INDIGENOUS PEOPLES – ARTICLE 15

“Indigenous peoples have the right to the dignity and diversity of their cultures, traditions, histories and aspirations which shall be appropriately reflected in education and public information”

A call for disaggregated, meaningful data in follow up reports.
WHO’S COMMISSION ON THE SOCIAL DETERMINANTS OF HEALTH A ‘MINIMUM HEALTH EQUITY SURVEILLANCE SYSTEM’.

As part of the system, ‘good-quality data on the health of Indigenous Peoples should be available, where applicable’.

A call for disaggregated, community-relevant data during an Indigenous-focused social determinants meeting in Adelaide in 2009.
INTERNATIONAL INDIGENOUS DATA SOVEREIGNTY

TE MANA RARAUNGA MAORI DATA SOVEREIGNTY NETWORK
Advocating for the development of capacity and capability across the Māori data ecosystem including:
- Data rights and interests
- Data governance
- Data access and control
- Data storage and security

OWNERSHIP, CONTROL, ACCESS, AND POSSESSION
OCAP in Canada, governing research and data

FIRST NATIONS DATA GOVERNANCE INITIATIVE
Nation-based, community-driven data governance

INTERNATIONAL INDIGENOUS DATA SOVEREIGNTY NETWORK
Linking efforts across the globe, including Australia, Canada, New Zealand, Peru, Sweden, and others.
TRIBAL DATA SOVEREIGNTY IN ACTION

TRIBAL LEADER VIEWS: Rodriguez- Lonebear, D., doctoral research interviews with 15 tribal leaders in July 2015

TRIBAL CENSUSES: Ho-Chunk Nation (WI)  
Laguna Pueblo (NM)

NCAI SURVEY OF TRIBAL LEADERS AND STAFF:
567 federally recognized tribes
Types of data
Data governance

TRIBAL EFFORTS CAPACITY AND CAPABILITY

SECTOR OR POPULATION SPECIFIC EFFORTS

US CENSUS

US INDIGENOUS DATA SOVEREIGNTY NETWORK
what may be possible?
The USIDSN seeks to link its members to share stories about data initiatives, successes, challenges, and resources.
HOST ORGANIZATION: NNI

ADMINISTRATIVE AND RESEARCH SUPPORT
COORDINATION OF ADVISORY BOARD ACTIVITIES
WEB HOSTING
LISTSERV MAINTENANCE
USIDSN ADVISORY COUNCIL

TRIBAL LEADERS & STAFF
*Joe Garcia (Ohkay Owingeh)
Head Councilman, Ohkay Owingeh Pueblo

Travis Jansen (Sicangu Oyate Lakota)
Legislative Director, Rosebud Sioux Tribe

ACADEMIA
Dr. Randall Akee (Native Hawaiian)
Department of Public Policy
UCLA

Dr. Matthew Snipp (Cherokee)
School of Humanities and Sciences
Stanford University

Dr. Nenibaa’ Garrison (Navajo)
The Treuman Katz Center for Pediatric Bioethics
Seattle Children’s Hospital

Dr. Stephanie Carroll Rainie** (Ahtna Athabaskan)
Native Nations Institute and College of Public Health
University of Arizona

Desi Rodriguez-Lonebear** (Northern Cheyenne)
University of Arizona and University of Waikato

TRIBAL COMMUNITY DATA EXPERTS
*Eileen Briggs (Cheyenne River Sioux)
Executive Director, Cheyenne River Tribal Ventures

Pat Riggs (Tigua)
Consultant, Red Vision Strategies

POLICY ADVOCATES
Dr. David Sanders (Oglala Lakota)
Research Director
American Indian College Fund

Liz Medicine Crow (Haida, Tlingit)
President/CEO
First Alaskans Institute

Dr. Malia Villegas (Sugpiaq/Alutiiq)
Director, Policy Research Center
National Congress of American Indians

Abigail Echohawk (Pawnee)
Co-Director & Tribal Liaison, Partnerships for Native Health
Washington State University

Gaps: IT, Legal, Business Entrepreneurs
Mentoring: Andrew Martinez,
University of Arizona
*Denotes Co-Chairs **Denotes Co-Founders
NETWORK MEMBERSHIP

Data users
Tribal leaders
Researchers
Policymakers and planners
Businesses
Service providers
Community advocates
Information & communication technology providers

Approximately 70 members

Need not be Indigenous so long as interested in furthering the aims of Indigenous data sovereignty in the US
CHARTING THE COURSE

1. Building support and resources for data governance

2. Mentoring and building capacity and capability

3. Connecting domestically & internationally for strategies, resources, and ideas
CHALLENGES & OPPORTUNITIES

Number and diversity of tribes and contexts

Moving beyond silos

Meeting the demand

Bridging tribal leaders and data warriors

Funding

Many voices and contributors, intertribal data agenda, regional hubs

Collaborating, teaching, technical assistance, mentoring

Forums, op eds, policy briefs

Foundations, feds, tribes
“Sovereignty as tribal nations was given to us by the Creator. It is sacred. Data to exercise our sovereignty is also sacred.”

-Tribal Leader at 2015 NCAI Mid-Year Conference

THANK YOU TO OUR FUNDERS

Udall Foundation
CIVILITY, INTEGRITY, CONSENSUS

Partnerships for Native Health

The University of Arizona
NATIVE NATIONS INSTITUTE
Founded by the Udall Foundation & the University of Arizona
Strengthening Indigenous Governance

National Institute of Demographic and Economic Analysis
Te Rūnanga Tōtari Tatauranga

Ngā Pae O Te Māramatanga