

Tribal Data Sovereignty and the Critical Role of Data in Public Health Governance

Heather Erb, Attorney at Law
American Indian Health Commission for Washington State
heather@erblawfirm.com





aihc

The American Indian Health Commission was created in 1994 by Washington's federally recognized tribes, urban Indian health organizations, and other Indian organizations to address tribal-state health issues. AIHC's mission is to improve the health status of American Indian and Alaska Native (AI/AN) people through tribal-state collaboration on health policies and programs. The Commission's work is directed by the 29 federally-recognized Tribes and 2 urban Indian health organizations in Washington. Delegates are officially appointed by tribal councils and urban Indian health organization boards to represent each individual Tribe and urban Indian health organization.

Recent Examples of Barriers to Tribal Data Sovereignty and Tribal Jurisdiction

1. State responding to national media requests that include tribal data without tribal input
2. State government use of non-official data about Tribes in official public documents without Tribe's permission
3. State sharing individual Tribes' vaccine allocations without Tribe's permission
4. State or local government impeding tribal health jurisdiction's access to public health data essential to exercising their public health authority and performing their governmental functions

Tribal Governments Are Public Health Jurisdictions with the Inherent Right to Control Their Data

Tribal Nations' inherent sovereign authority to administer the collection, ownership, and application of their own data is rooted in a tribal nation's right to govern their people.

See "[Data Governance Strategies for States and Tribal Nations](#)", Network for Public Health Law.



**FEDERAL AND
STATE LAWS
RECOGNIZE
TRIBAL NATIONS
AS
PUBLIC HEALTH
JURISDICTIONS**

See 45 CFR § 164.501 and
RCW 43.70.512(1)

**Examples of Exercising
Tribal Public Health Authority & Jurisdiction**

Accessing and Using
Public Health Data
(Washington Disease
Reporting System)

Accessing and
Dispensing Vaccines

Emergency Response



Data Sovereignty

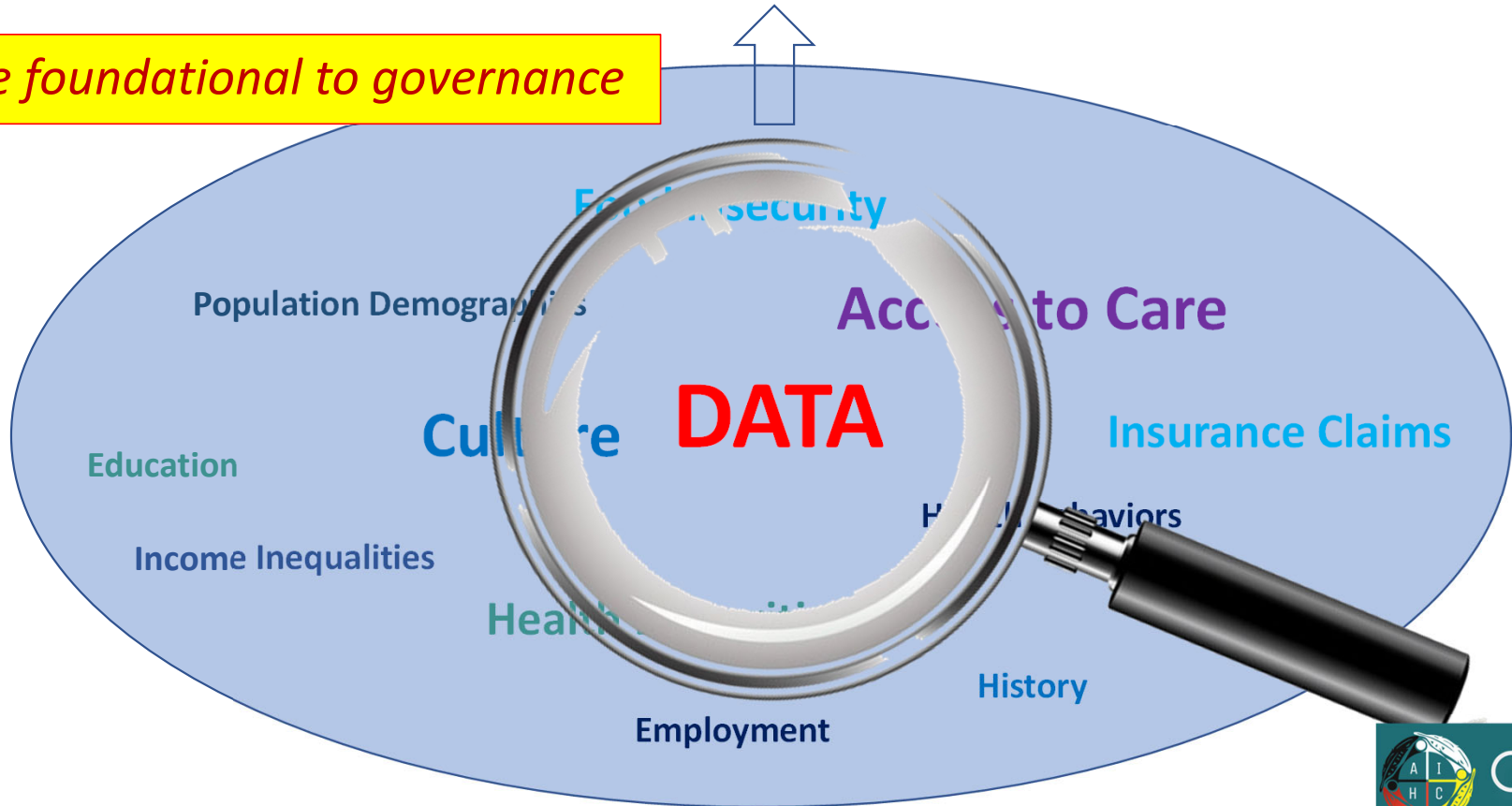
“Indigenous data sovereignty is the right of a nation to govern the collection, ownership, and application of its own data”

- U.S. Indigenous Data Sovereignty Network,
<http://usindigenousdata.arizona.edu/about-us-0>



GOVERNANCE

Data are foundational to governance



TRIBE'S
PUBLIC HEALTH
AUTHORITY IS
INHERENT AND
INCLUDES DISEASE
SURVEILLANCE

“Public health authority refers to the authority of a government to engage in public health activities as part of its official duties.... No law, federal or Tribal, is needed to grant Tribes the authority to engage in public health activities. Protecting the public’s health, safety, and welfare is among the core powers and duties of sovereign governments. Engaging in isolation, quarantine, case investigations, contact tracing, and **disease surveillance are essential public health services**. These powers are inherent to all sovereign nations, including Tribes. Some Tribal constitutions explicitly refer to the authority to protect and promote health and welfare as a power of the government.”

Aila Hoss, *Toward Tribal Health Sovereignty*, 419 U. Wis. L. Rev. 2022 (2022), *emphasis added*. Find this article in [Wisconsin Law Review Symposium, The Restatement of the Law of American Indians](#).



Four Core Tribal Data Sovereignty Principles





Principle # 1

Only a Tribe has the sovereign authority to determine how their data may or may not be used.

*See Network for Public Health Law, <https://www.networkforphl.org/resources/data-governance-strategies-for-states-and-tribal-nations/?msclkid=d41c5fbd92d11ecb58179dd429446a4>





Principle # 2

“When a jurisdiction reports on or about American Indian or Alaska native peoples, it should meaningfully partner and consult with Tribal leaders on the analysis and interpretation of the data.”

*See Network for Public Health Law, <https://www.networkforphl.org/resources/data-governance-strategies-for-states-and-tribal-nations/?msclkid=d41c5fbd92d11ecb58179dd429446a4>





Principle # 3

Tribes retain an ownership interest in data, even when the Tribe's data are located in a state, federal or other dataset. This interest remains when the Tribe's data are aggregated with other data.

*See PolicyLink, [10-Design-Principles-For-Online-Data-Tools.pdf \(nationalequityatlas.org\)](#) page 15





Principle # 4

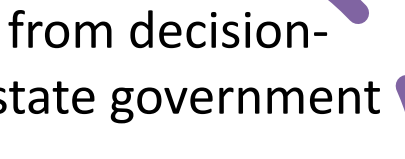
Tribes must have equitable access to data needed to perform their governmental duties.

*See PolicyLink, [10-Design-Principles-For-Online-Data-Tools.pdf \(nationalequityatlas.org\)](https://www.nationalequityatlas.org/files/documents/10-Design-Principles-For-Online-Data-Tools.pdf) page 14





Three Major Barriers to Tribal Data Sovereignty and Tribal Jurisdiction

- 
1. **Exclusion of Tribal nations** from decision-making/input on federal and state government use of tribal and AI/AN data.
 2. **Lack of federal and state data sharing agreements** that protect Tribal and AI/AN data and recognize Tribal ownership in data about their Tribe and their people.
 3. Lack of federal and state government mechanisms to **provide Tribal nations equitable access to AI/AN data** necessary for Tribes to perform their governmental duties.

Tribes and Urban Indian Health Organizations Must Have

Access to other entities' data

- States
- Federal
- Epicenters

Input on how other entities use and share data regarding Tribes and AI/AN

Infrastructure to collect, store, analyze, and share their own data

- Information management systems (software)
- Hardware
- Codes, Data Sharing Agreements, Data Use Agreements
- Workforce



Overview of Washington Department of Health (DOH)- Tribe Data Sharing Agreement



Tribal Data Sharing Agreements

Key Provisions

An agreement that closely aligns with legal principles of Tribal data sovereignty includes:

1. Requirements for government-to-government relationship through Tribal decision-making/input on federal and state government use of tribal and AI/AN data
2. Requirements for state to protect Tribal and AI/AN data
3. Recognition Tribal ownership in data about their Tribe and their people
4. Establishes more equitable access to AI/AN data to perform their governmental duties



Provision #1:
Inclusion of Tribal
governments
through decision-
making/input on
federal and state
government use
of tribal and
AI/AN data

**APPENDIX E: TRIBAL DATA SOVEREIGNTY
COMMITTEE**

1.1. Purpose. The Tribal Data Sovereignty Committee (TDSC) provides a venue to build government-to-government relationships regarding tribal data governance and to provide subject matter expertise in addressing the sharing and usage of data and information regarding AI/AN and Tribes to assure the protection of tribal data sovereignty. The TDSC shall not serve as a substitute for DOH's requirement to conduct tribal consultation pursuant to RCW 43.376.



Provision #2:
Requirements for
state to protect
Tribal and AI/AN
data

5. DATA GOVERNANCE

Subject to any limitations provided in subsection 5E, this section provides the conditions under which the Washington State DOH collects, manages, uses, discloses, and safeguards Tribal and American Indian and Alaska Native Information and data.



Provision #3: Recognition of Tribal ownership of data about their Tribe and their people

3. OWNERSHIP OF DATA

Unless otherwise provided by law and subject to the restrictions and limitations in this agreement, [INSERT THIS LANGUAGE FOR TRIBES ONLY] the [NAME OF TRIBE] and DOH have joint ownership in data and information regarding the Tribe, its tribal citizens, and persons who reside within the Tribe's jurisdiction, under this Agreement. These data and information include, but are not limited to, data in the DOH database systems referenced in any Exhibits attached to this Agreement.



Provision #4: Establishes more equitable access for Tribes to AI/AN data needed to perform their governmental duties

4. ACCESS TO DOH DATASETS/DATABASES

- Statewide read of WDRS for COVID-19 events (See Exhibit I)**
- Statewide write access of WDRS for COVID-19 events**
- Linked COVID-19 Immunization Administration Data in WDRS (See Exhibit II)**
- Linked COVID-19 Death Data in WDRS (See Exhibit III)**
- Linked COVID-19 syndromic surveillance data in WDRS (See Exhibit IV)**
- Linked COVID-19 CREST case investigation data in WDRS (See Exhibit V)**
- COVID-19 WDRS system read access for the Urban Indian Health Institute**
- COVID-19 CREST system read access (case and contact investigation data) for Tribes (See Exhibit VI)**
- COVID-19 CREST system write access (case and contact investigation data) for Tribes**
- COVID-19 CREST system read access for Urban Indian Health Institute**
- Read access to WDRS for non-COVID conditions. (See Exhibit XX)**
- Write access to WDRS for non-COVID conditions.**
- Washington State Immunization Information System or WAIS Viewing (See Exhibit XY)**
- Washington State Immunization Information System or WAIS Exchanging (See Exhibit XY)**

[NAME OF TRIBE OR UIHI] can choose to request access to additional DOH datasets and databases, and any access provided to additional datasets and databases will be added in the form of an Exhibit attached to this Agreement and executed by both



Tribes Share Best Practices and Lessons Learned on Data Uses During the COVID-19 Response

- What data did you use during the COVID-19 response?
- How did you access these data?
- What was your process?
- How did you protect your data?
- How did you share data with your neighboring county or the state?
- What can we do to improve access to data for your Tribe?
- What other work is needed to protect tribal data and assure Tribes' access to data?





Thank you!

Heather Erb, heather@erblawfirm.com

Lou Schmitz, lou.schmitz.aihc@outlook.com

