



NativeDATA

A Data Sharing Resource for
Native Peoples and Organizations

Tribal Data Sovereignty

Tribes have the right to data sovereignty. This includes being in control of how Tribal data is collected, owned, and used. The principles outlined below provide a starting point for understanding Tribal (or Indigenous) data sovereignty. Some of these principles apply to data on American Indian and Alaska Native people off Tribal lands.

1. Tribes Are Sovereign Nations.

As sovereign nations, Tribes have the power to govern their people, land, and resources without interference from other jurisdictions.^{1,2} Federally recognized Tribes have a government-to-government relationship with the U.S. government, and state recognized Tribes have a government-to-government relationship with the states in which they are recognized.

Recommended resources:

[This guide](#) provides an overview of the principles of Tribal sovereignty.

2. Tribes Are Public Health Authorities.

Public health authority is the power a sovereign government has to protect the health, safety, and welfare of its citizens.³ As sovereign nations, Tribes have the power to define how they will use this authority to protect and promote the health of their communities.⁴ While Tribes do not need the recognition of the U.S. government to use their public health authority,³ the federal government recognizes Tribes as public health authorities under federal law (e.g., the Health Insurance Portability and Accountability Act or HIPAA).⁵ This authority gives Tribes and some Native-serving organizations, including Tribal Epidemiology Centers, the ability to obtain certain types of protected health information from federal, state, county, and other HIPAA covered entities for public health purposes.⁶

Recommended resources:

[This handout](#) provides an overview of public health authority status.

3. Tribal Data Sovereignty Is A Right.

Tribal data sovereignty is the inherent right Tribes have to control the collection, ownership, and use of their own data.⁷ Data are an important tool used by sovereign nations to inform policies and decision-making. Data are also key to building Tribal health systems that protect and promote health for current and future generations.^{7,8}

4. Data Sharing Should Support Tribal Data Sovereignty.

Legitimate [data sharing agreements](#) and protocols support Tribal data sovereignty. They support Tribes and Native-serving entities in:

Obtaining data held by federal, state, county, and other data holders

Tribes and Native-serving organizations should be able to obtain data from local, state, and federal governments and other data holders through [data agreements](#) that uphold Tribal sovereignty and Tribal public health authority. Data sharing can help Tribes and Native-serving organizations obtain data to inform health policies and decision-making.

Controlling data shared with external entities

Tribes, urban Indian communities, and Native-serving organizations have the authority to [decide when it is appropriate to share their data](#). When deemed appropriate, Tribes and Native-serving organizations have the authority to share data through data agreements. External entities requesting data must recognize Tribal law, code, and policies related to research, data collection, and data sharing. They must also participate in Tribal research review and data governance boards when attempting to conduct research on Tribal lands or with Tribal citizens.⁷

Recommended resources:

1. This policy brief defines Indigenous data sovereignty and provides recommendations for Tribes, Native-serving organizations, non-Tribal governments, and other partners.
2. This white paper describes principles of data sharing with American Indian and Alaska Native communities. While focused on research, some principles can inform data sharing when done for public health purposes.

Need Help?

These [data supports](#) can help you understand what data are available for you, how to navigate the data sharing process, and support you in learning about your Tribal data sovereignty and [public health authority status](#).

References:

1. National Congress of American Indians. Tribal Nations and the United States: An Introduction. 2020. Available at: <https://www.ncai.org/about-tribes>.
2. Network for Public Health Law. Fact Sheet: Data Governance Strategies for State and Tribal nations. 2020. Available at: <https://www.networkforphl.org/wp-content/uploads/2020/09/Data-Governance-Strategies-for-States-and-Tribal-Nations-.pdf>.
3. Aila Hoss. Tribes are Public Health Authorities: Protecting Tribal Sovereignty in Times of Public Health Crisis, Issue Brief Prepared for the Great Lakes Inter-Tribal Epidemiology Center. 2021. Available at: <https://static1.squarespace.com/static/5930883f17bffc-fab9deb18d/t/5f396bd9d513670e3c76471/1609799358131/Tribes+are+Public+Health+Authorities+FINAL.pdf>.
4. Centers for Disease Control and Prevention Public Health Law Program. Tribal Public Health and the Law: Selected Resources. 2016. Available at: <https://www.cdc.gov/phlp/docs/tribal-ph-resource.pdf>.
5. 45 CFR § 164.501.
6. 45 CFR § 160.103.
7. Carroll SR, Rodriguez-Lonebear D, Martinez A. Indigenous Data Governance: Strategies from United States Native Nations. 2019. Data Science Journal, 18(31): 1-15.
8. Rainie, Stephanie Carroll, Desi Rodriguez-Lonebear, and Andrew Martinez. Policy Brief: Indigenous Data Sovereignty in the United States. 2017. Tucson: Native Nations Institute, University of Arizona. Available at: http://nni.arizona.edu/application/files/1715/1579/8037/Policy_Brief_Indigenous_Data_Sovereignty_in_the_United_States.pdf.



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Got questions? Contact us at ideanw@npaihb.org or visit NativeDATA.npaihb.org.

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