



## TRIBAL HEALTH Fact Sheet

# Data Governance Strategies for States and Tribal Nations

The health and wellness of Tribal nations depend on effective data collection and analysis. Data are essential for robust public health practices, including surveillance, epidemiological investigation, research, program development, implementation and evaluation. Tribes may lack capacity to collect data needed to improve Tribal health and well-being, and other jurisdictions may have already collected the Tribe's data as part of their ongoing surveillance. There are opportunities for Tribes and other jurisdictions to mutually assist each other; unfortunately, a lack of trust has interfered with data sharing arrangements.


Thus, this fact sheet focuses on strategies states should take to support indigenous data sovereignty. Sound and effective governance strategies for data sharing among states and Tribal nations are integral for ensuring that trust is maintained, and data privacy and security risks are appropriately managed.<sup>1</sup> The keys to establishing and maintaining trust are respecting Tribal data sovereignty and honoring the United States' trust responsibility to Tribal nations.

## Tribal Sovereignty

[Tribal nations](#) are separate and sovereign jurisdictions. The United States Constitution as well as the United States Supreme Court, through a series of cases known as the Marshall Trilogy, recognize that Tribes are sovereign nations with the inherent authority to determine the form of Tribal government, to make their own laws, and to be ruled by them.<sup>2</sup>

Today, there are three types of sovereign entities within the United States - Tribes, the federal government, and state governments. The federal government has committed to certain responsibilities to Tribes and Indians, known as the trust responsibility. Professor Matthew L.M. Fletcher describes the United States' trust responsibility as "a legal duty of preserving Indian and Tribal property and autonomy to the maximum extent allowable in the national interest."<sup>3</sup> In contrast, states have no authority to regulate Tribes, except as defined by Congress or by the federal government through its trust obligations. Tribal sovereignty is critical to Tribal nation building and provides the legal vehicle for Tribes to govern their nations without interference from federal, state, or local jurisdictions.<sup>4</sup>

As sovereign nations, Tribes have inherent authority to protect their Tribal citizens' health and wellness and provide public health services as they determine best. [Read more about Tribal public health law](#) and [Tribal self-determination](#). To govern public health service delivery to their people, Tribal nations have the authority to



administer the collection, ownership, and application of their own data, which is known as indigenous data sovereignty according to the [National Congress of American Indians](#) (NCAI). The NCAI is the oldest, largest and most representative national organization representing Tribes.

## Establishing Data Partnerships

Where Tribes do not have capacity to collect data on Tribal citizens themselves, they may partner with other jurisdictions, such as state governments. From 2016 to 2018, NCAI conducted a [Tribal Data Practices Survey](#) to understand the type of data used by Tribes; collection, management, and data reporting practices; and the data that Tribes need. Importantly, the survey report indicates that 83% of respondents agreed that it is extremely important to collect or access data on Tribal citizens for governance purposes. The report also states that not all Tribes have adequate resources to collect their own data and identifies partnerships between Tribes and academic, corporate, and government sectors as potentially mutually beneficial.

To understand any given population's health and wellness, data may come from a variety of sources from within or from outside the jurisdiction – public health, clinical care, claims data and research, for example. Jurisdictions also utilize data from other sectors such as environmental measures, climate measures, food availability, and transportation options. Adoption and use of a governance framework enables state governments to address Tribal partnership in project design, honor indigenous data sovereignty, and grow trust.


## Establishing Data Governance Principles

When state governments and Tribes share data, it is important for all parties to establish strong data governance programs; data governance may also be referred to as data stewardship. The [National Committee on Vital and Health Statistics \(NCVHS\)](#), which serves as the public advisory body to the Secretary of Health and Human Services for health data, statistics, privacy, and national health information policy and the Health Insurance Portability and Accountability Act (HIPAA), [defines a data steward's](#) role as “ensuring appropriate collection, management, use, disclosure, or safeguarding of information.” Accordingly, before a data steward will share data, he or she must trust that the information will be used, disclosed, managed, and safeguarded appropriately. In short, strong data governance promotes more data sharing and data use.

Data governance is a process that is grounded in a principle-based framework. Data sharing between state governments and Tribal nations must be grounded in trust and defined, supported, and enforced through a robust governance process. Read more about data governance [here](#).

There are many different governance frameworks available with varying foci. All parties should select and adopt a framework that aligns with their mission, vision, and values. State governments and Tribes might evaluate starting with the [NCVHS Stewardship Framework](#) which identifies eight elements:

1. **Openness, transparency, and choice** – what information is being collected and why, consent options
2. **Purpose specification** – the initial purpose of the data collection and its downstream uses are defined and made explicit at the point of collection
3. **Community engagement and participation** – whether and how communities should be involved in decision-making about data
4. **Data integrity and security** – evaluation of confidentiality, integrity and availability risks to the data and a plan to address those risks

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5. **Accountability** – identification of a person or entity responsible for data governance at each stage of the data lifecycle
  6. **Protecting de-identified data** – ensuring that data are de-identified, as appropriate, and have administrative safeguards, as needed
  7. **Attending to the risks of “enhanced” data sets** – ensuring that re-identification risks are appropriately managed when data sets are merged
  8. **Stigma and discrimination** – ensuring that data uses don’t stigmatize or result in negative attitudes towards communities

Other frameworks to consider include: [TrustArc-Nymity Integrated Privacy Frameworks](#), [AICPA/CICA’s Generally Accepted Privacy Principles](#) and [The NIST Privacy Framework: A Tool for Improving Privacy through Enterprise Risk Management](#).

As Tribal nations continue to expand their capacity to exercise their sovereign right to collect their own data, best practices in data governance are emerging in Indian country. [Tribal Data Practices Survey](#). Tribes might lean on the work of their growing Tribal data champions and evaluate how they might shape the NCVHS Stewardship Framework to meet Tribal needs. Professor Aila Hoss provides a lens to evaluate a proposed governance framework’s appropriateness for Tribal adoption:

“Inquiry: In responding to a Tribal public health issue, have you:

1. ensured that Tribal Sovereignty is respected and promoted, and explored strategies that can be implemented relying on Tribal inherent authority?
2. evaluated whether any federal Indian laws are implicated by the issue?
3. considered utilizing Tribal law tools to address the issue such as authorities in the Tribal constitution, Tribal codes, reliance on Tribal case law or customary law?
4. assessed whether legal strategies proposed would perpetuate structural violence against a Tribe or American Indian and Alaska Native communities?  
ensured actions by local, state, and federal actors include Tribal engagement and consultation?”  
[A Framework for Tribal Public Health Law, p. 27](#).

With regard to the principle of community engagement and participation, [Powering Health Equity Action with Online Data Tools: 10 Design Principles](#) states that 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*. The NCVHS heard from American Indian Tribal experts about the impacts from a lack of data governance, particularly with respect to a failure to engage in Tribal government consultation and decision-making that involved Tribal citizens. This governance lapse and others caused harm to the Tribe and its people and resulted in a breach of trust that is likely not overcome today.

Governance is built through a policy framework, a trust agreement, and a decision-making oversight body. Data sharing collaboratives develop policies to implement each principle within the governance framework. Further, all parties to a data sharing collaborative agree that they will be bound by the governance framework and will implement policies through a trust agreement which is also known as a [data sharing agreement](#). The Urban Indian Health Institute’s [Best Practices for American Indian and Alaska Native Data Collection](#) recommends that *states execute a data use agreement with Tribes so that they cannot release the Tribe’s identifiable data without consent*. Execution of a data sharing agreement provides a safeguard so that indigenous data sovereignty is not violated.

States should consult their [public records laws](#) to ensure that they will be able to protect Tribal data in compliance with a data use agreement. *Jurisdictions might evaluate whether applicable state law has a public records exemption that will accommodate the state’s promise to hold Tribal data as confidential and to not release the data without the Tribe’s permission*. A common exemption to state public records laws is where

another law requires that the information be held as confidential. [A Framework for Tribal Public Health Law](#) states that Tribal public health law may be found in: Tribal constitutions, Tribal codes, Tribal case law, Tribal customary law and culture, and in intergovernmental coordination. If Tribal law requires that state government not disclose its data without consent, a state public records exemption is likely met.

## Conclusion

[Including Tribal members in public health practice and research](#) is important for identifying disparities and equitably allocating resources. [Read more](#). States need to improve their data governance approach to respect and honor indigenous data sovereignty, identify disparities, and then equitably address them. Adoption of data governance programs will also provide benefits to state public health programs through improved data sharing. Governance body oversight and potential application of penalties for non-compliance with the data sharing agreement may provide Tribal nations with the confidence and trust to allow their data to be shared. Historical trauma and structural, cultural, and political actions against Tribes may only begin to be assuaged through partnership, real commitment to data governance, and trust.

## SUPPORTERS



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<sup>1</sup> While governance is necessary for all data sharing amongst federal, state and city governments and tribes, this article focuses on data sharing between states and Tribes.

<sup>2</sup> Fletcher, M., *Principles of Federal Indian Law*, p. 5 (West Academic, 2017).

<sup>3</sup> *Id.* at 127 (West Academic, 2017).

<sup>4</sup> *Id.* at 164.