

Data Access and Use Toolkit

TO SUPPORT TRIBAL
PUBLIC HEALTH

AUGUST 2026



CENTER FOR PUBLIC HEALTH
**WORKFORCE
DEVELOPMENT**
ASPPH

What's inside the toolkit?

Who created this toolkit?

Tribal Legal Experts

Advisory Collaborative

ASPPH

Why is it important for Tribes to access public health data?

What rights does a Tribe have to its public health data?

What tools can Tribes use to govern and access their public health data?

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Acknowledgement

This toolkit is part of a larger effort to provide legal technical assistance free of charge to federally recognized Tribes pursuing the legal and/or governance foundations needed to access their data from a U.S. state and/or local public health authority.

The creation and sharing of knowledge is a reciprocal process—one rooted in mutual respect, trust, and responsibility. In the spirit of reciprocity, it is our intention that this toolkit and related project efforts give back to the Tribal Nations whose insights and experiences made it possible, ensuring that data practices benefit communities as much as they inform research, policy, and public health.

We extend our gratitude to the Tribal leaders, data practitioners, and community partners who contributed their time, knowledge, and perspectives to ensure that this project reflects Indigenous values, priorities, and governance principles. Their guidance has shaped this toolkit into a resource that not only intends to enhance Tribal data access and use but also strengthens the capacity of Tribal Nations to make informed, community-driven decisions.

We acknowledge that this project builds upon generations of advocacy and resilience from Indigenous peoples who continue to protect their cultural, environmental, and intellectual resources.

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This toolkit is designed for Tribes pursuing the legal and/or governance foundations needed to access their data from a U.S. state and/or local public health authority.

The toolkit includes a Model Tribal Data Sharing Code – a legal tool developed through this project – that Tribes may adapt to their needs, as well as a step-by-step Implementation Guide to tailor the tool to the specific needs of each Tribe.

The toolkit also features a bank of free resources for Tribes interested in data access, sharing, and use, including Data Sharing Agreement templates.



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Who created this toolkit?

In 2024, the U.S. Centers for Disease Control and Prevention (CDC) awarded funding to the [Association of Schools and Programs of Public Health \(ASPPH\) Center for Public Health Workforce Development](#) to accelerate the exchange of public health data from state and local public health authorities to federally-recognized Tribes.

ASPPH has engaged an Advisory Collaborative of Tribal public health and Tribal data governance experts to ensure all project efforts center Tribal sovereignty and benefit Tribal Nations as much as possible.

ASPPH and the Advisory Collaborative worked with Tribal Legal Experts from the [Native American Law Practice at Kaplan Kirsch LLP](#) to develop the Model Tribal Data Sharing Code and Implementation Guide included in this toolkit and are now working to provide technical assistance free of charge to federally-recognized Tribes pursuing the legal and/or governance foundations needed to access their data from a U.S. state and/or local public health authority.

Funding for this project is provided through PW-24-0080 Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health from the Centers for Disease Control and Prevention (CDC) of the Department of Health and Human Services (HHS) as part of financial assistance award no. NU38PW000021 awarded to the Association of Schools and Programs of Public Health (ASPPH). The contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC or HHS.

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Tribal Legal Experts

Kaplan Kirsch LLP, Native American Law Practice

The Tribal Legal Experts have created the Model Tribal Data Sharing Code and Implementation Guide featured in this toolkit. They are available to provide technical assistance free of charge to federally recognized Tribes pursuing the legal and/or governance foundations needed to access their data from a U.S. state and/or local public health authority.



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Advisory Collaborative

Tribal Public Health Data Access and Use Project

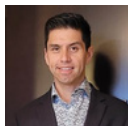
The Advisory Collaborative provides subject matter expertise into the formation and implementation of ASPPH's project plan, strategy to engage federally recognized Tribes, and the development of tools for Tribes.



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Tribal Public Health Data Access and Use Project

ASPPH manages all aspects of the project and leads the Advisory Collaborative in ensuring activities center Tribal sovereignty and deliver meaningful benefits to Tribes. In partnership with the Tribal Legal Experts, ASPPH coordinates the development of practical tools and technical assistance free of charge for federally recognized Tribes pursuing the legal and/or governance foundations needed to access their data from a U.S. state and/or local public health authority.



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Why is it important for Tribes to access public health data?

The COVID-19 pandemic made clear that infectious diseases do not obey jurisdictional boundaries. To track disease spread, respond to emergencies, and manage ongoing public health challenges, Tribal, state, and local governments all need timely and relevant public health data. This includes case data, syndromic surveillance data, diagnostic testing data, vaccine administration data, vital statistics, and hospital capacity information. Robust policy-based tools that support the operationalization of Tribal sovereignty and facilitate Tribal data sharing are essential to enable the flow of information across jurisdictions.

Despite their sovereign status, many federally recognized Tribes face significant barriers to accessing public health data, including data regarding their citizens and communities, when that data is collected and controlled by state, city, or county entities. Without access to this data—and without fair, formal mechanisms for data exchange—Tribes may face delays in responding to public health threats, and their data is at risk of misuse or inadequate protection. Strong, respectful data sharing frameworks that honor Tribal sovereignty are critical to ensuring that Tribes can care for the health and well-being of their communities.

INTERESTED IN MORE INFORMATION?

Scan the QR code and let us know! A Tribal Legal Expert will contact you.



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What rights does a Tribe have to its public health data?

Tribal sovereignty is the inherent authority of Tribal Nations to govern themselves. It is rooted in the fact that Tribes are distinct, self-determining political communities that pre-date the United States. Federally recognized Tribes have their sovereignty formally acknowledged by the U.S. government, including in the United States Constitution.

Tribal data sovereignty refers to the right of Tribal Nations to govern the collection, ownership, access, and use of their data. For federally recognized Tribes, this includes access to health data housed by federal, state, and local public health entities.

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What tools can Tribes use to govern and access their public health data?

Tribes may use a variety of legal, administrative, and governance tools to support the access, sharing, and stewardship of public health data. These tools help establish clear expectations between Tribes and state or local public health jurisdictions while reinforcing Tribal authority over data that affect Tribal citizens and communities. Depending on the purpose and scope of a data-sharing relationship, Tribes may use data sharing agreements to establish broad terms for data exchange, data use agreements to define permitted uses of specific datasets or projects, and Tribal data sharing or data governance codes to establish Tribal laws, standards, and requirements governing the collection, access, use, disclosure, and protection of data.

These tools are most effective when grounded in Tribal sovereignty and aligned with Tribal governance structures, cultural values, and public health priorities. Tribes may also rely on resolutions, Institutional Review Board (IRB) protocols, research review processes, policies, and memoranda of understanding or agreement to support implementation and clarify roles and responsibilities. Together, these mechanisms can help ensure that data are collected, shared, used, and protected in ways that benefit Tribal communities while supporting effective public health partnerships and decision-making.

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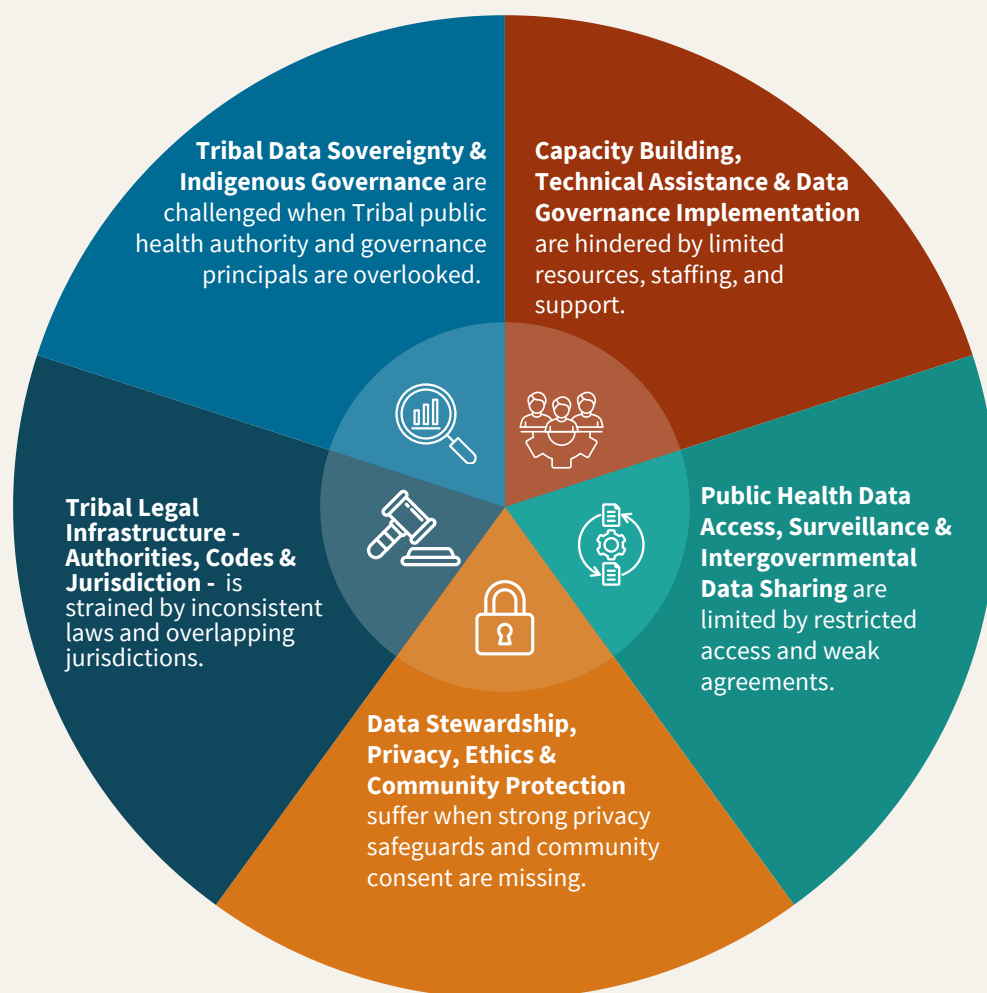
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How are Tribal organizations addressing challenges to data sovereignty?

Tribal public health authorities often encounter significant challenges in exercising their data sovereignty.



Supporting Tribal data sovereignty means **addressing these barriers and ensuring that Tribes have the legal, technical, and relational tools they need to access, use, and protect their data** in ways that align with their values and ways of governing.

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Resources for Tribes by Theme

Tribal Nations, Tribal organizations, Tribal Epidemiology Centers, Indigenous researchers, and their partners have been addressing these challenges for decades. They have led and continue to lead the development of guidance, tools, and frameworks designed to protect Tribal interests while enabling appropriate data access and use. These efforts demonstrate both the depth of expertise within Tribal communities and the growing body of practical approaches available to support Tribal data governance.

The resources below are listed by theme and represent a selection of the many tools, templates, reports, and guidance documents currently publicly available.* The list is not intended to be exhaustive; rather, it highlights key examples that may help inform policy development, partnership agreements, and data governance efforts.

Themes

1

Tribal Data Sovereignty & Indigenous Governance

2

Capacity Building, Technical Assistance & Data Governance Implementation

3

Public Health Data Access, Surveillance & Intergovernmental Data Sharing

4

Data Stewardship, Privacy, Ethics & Community Protection

5

Tribal Legal Infrastructure: Authorities, Codes & Jurisdiction



Tribal Data Sovereignty & Indigenous Governance

Rights and authority of Tribal Nations to govern, control, protect, and decide how data about their peoples, lands, and communities are collected, accessed, interpreted, and shared. Includes Indigenous governance principles, sovereignty frameworks, and cultural knowledge protections.

Alberta First Nations Information Governance Centre

[The First Nations Principles of OCAP®](#)

Albuquerque Area Southwest Tribal Epidemiology Center

[Data Sharing Agreement for Use of the Southwest Indigenous Database](#)

American Indian Health Commission

[Tribal Data Sovereignty and Data Privacy Resources](#)

Global Indigenous Data Alliance

[CARE Principles for Indigenous Data Governance](#)

Governor's Indian Health Advisory Council

[Tribal Data Sharing Agreement Checklist](#)

Northwest Portland Area Indian Health Board

[Northwest Tribal Epidemiology Center Data Governance Handbook](#)

Northwest Territories Indigenous Knowledge Agreement

[Indigenous Knowledge Data-Sharing Agreement](#)

The Udall Center for Studies in Public Policy's Native Nations Institute

[Policy Brief \(Version 2\): Data Governance for Native Nation Rebuilding](#)

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Urban Indian Health Institute

[Best Practices for American Indian and Alaska Native Data Collection](#)

U.S. Indigenous Data Sovereignty Network

[Indigenous Data Governance Brief](#)

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Capacity Building, Technical Assistance & Data Governance Implementation

Practical supports needed to implement Tribal data governance systems, including training, technical assistance, workforce development, infrastructure building, and the operational processes for adopting codes, agreements, and policies.

American Medical Association

[Patient Access Playbook](#)

Code for America

[Interoperability & digital governance models](#)

The Network for Public Health Law

[Health Information and Data Sharing](#)

Northwest Portland Area Indian Health Board & National Indian Child Welfare Association

[Tribal Policy Guide](#)

State Data Sharing Initiative

[State Data Sharing Initiative Tools](#)

Tribal Information Exchange

[Sharing Agreements](#)

The Udall Center for Studies in Public Policy's Native Nations Institute

[Research and Policy Analysis](#)

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Public Health Data Access, Surveillance & Intergovernmental Data Sharing

Tribal access to datasets held by state and federal jurisdictions, government-to-government data flows, public health surveillance systems, interoperability, and the agreements or legal mechanisms that structure Tribal-local-state-federal data exchange.

Albuquerque Area Southwest Tribal Epidemiology Center

[Data Sharing Agreement for Use of the Southwest Indigenous Database](#)

Indian Health Service

[National Patient Information Reporting System \(NPIRS\)](#)

Indian Health Service

[TEC Data Access Guidance](#)

Massachusetts General Court

[An Act Requiring Certain Reports for Opiate Overdoses, Acts of 2015, Chapter 55](#)

National Indian Health Board

[CDC Public Health Datasets and Access Guide for Tribes and Tribal Epidemiology Centers](#)

Northwest Portland Area Indian Health Board

[Northwest Tribal Epidemiology Center Data Governance Handbook](#)

U.S. Centers for Disease Control & Prevention

[Guidance for Federally Recognized Tribes and TECs on Requesting CDC Public Health Data](#)

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U.S. Centers for Disease Control & Prevention, Office for State, Tribal, Local, and Territorial Support

[Tribal Epidemiology Centers Designated as Public Health Authorities Under the Health Insurance Portability and Accountability Act](#)

Washington State Department of Health

[Public Health Data Exchange for Promoting Interoperability](#)

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Data Stewardship, Privacy, Ethics & Community Protection

Responsible data practices, including privacy protections, data security, ethical rules for handling identifiable and sensitive information, community consent, research protections, and confidentiality.

Aila Hoss, Juris Doctor

[Publications](#)

Albuquerque Area Southwest Tribal Epidemiology Center

[Data Sharing Agreement for Use of the Southwest Indigenous Database](#)

American Medical Association

[Patient Data Privacy and Access Resources](#)

California Department of Health Care Access and Information

[Data Exchange Framework](#)

Heather Erb, PLLC

[Selected Presentations and Selected Publications](#)

Indian Health Service

[IHS Data Use Agreement \(DUA\) frameworks](#)

National Institutes of Health

[Data Management and Sharing Policy](#)

Northwest Portland Area Indian Health Board

[Northwest Tribal Epidemiology Center Data Governance Handbook](#)

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Tribal Legal Development Clinic, UCLA School of Law

[The Need for Confidentiality within Tribal Cultural Resource Protection](#)

U.S. Department of Health and Human Services, Office of Civil Rights

[Health Information Privacy](#)

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Tribal Legal Infrastructure: Authorities, Codes & Jurisdiction

Tribal legal powers, authorities, and statutory frameworks that underpin public health governance, surveillance authority, confidentiality, and jurisdiction. Includes Tribal codes, legal precedents, and structures.

Aila Hoss, Juris Doctor [Publications](#)

Albuquerque Area Southwest Tribal Epidemiology Center

[Data Sharing Agreement for Use of the Southwest Indigenous Database](#)

American Indian Health Commission

[Tribal Public Health Jurisdiction and Governance](#)

Commonwealth of Massachusetts

[Privacy and Confidentiality at DPH](#)

Indiana State Law

[Public health confidentiality & data governance statutes \(IN Code § 16-37-1-10 \(2024\)\)](#)

New Jersey State Law

[Public health confidentiality & data governance statutes \(NJ Senate Bill S332\)](#)

Northwest Portland Area Indian Health Board

[Northwest Tribal Epidemiology Center Data Governance Handbook](#)

Tribal Information Exchange

[Sharing Agreements](#)

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[The Model State Public Health Act](#)

UCLA Native Nations Law and Policy Center

[Native Nations Publications](#)

Urban Indian Health Institute

[Best Practices for American Indian and Alaska Native Data Collection](#)

West Virginia State Law

[Public health confidentiality & data governance statutes \(W. Va. Code §16-29G-8\)](#)



Tools for Tribes

The Tribal Public Health Data Access and Use Project is excited to offer Tribes new tools to use when pursuing the legal and/or governance foundations needed to access their data from a U.S. state and/or local public health authority. These tools are described and linked below.

MODEL TRIBAL DATA SHARING CODE

[CLICK HERE](#)

The Model Tribal Data Sharing Code provides a framework and adaptable language for developing Tribal law related to the receiving of health data from other governments and the sharing of health data with other governments. It is intended to support Tribal sovereignty, establish clear standards for data governance, and guide decision-making in data sharing relationships.

IMPLEMENTATION GUIDE

[CLICK HERE](#)

The Implementation Guide walks the reader through each step in adapting, adopting, and implementing the Model Tribal Data Sharing Code.



WORK WITH A TRIBAL LEGAL EXPERT

Through this project, Tribal Legal Experts from the [Native American Law Practice at Kaplan Kirsch LLP](#) are providing technical assistance free of charge to federally recognized Tribes pursuing the legal and/or governance foundations needed to access their data from a U.S. state and/or local public health authority.

Technical assistance may include general guidance, education, or support on legal topics or processes, but technical assistance alone does not create an attorney-client relationship or include legal advice.

If you are interested in more information, please [click here to let us know](#) and a Tribal Legal Expert will contact you.

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Implementation Guide

The Model Tribal Data Sharing Code (“Model Code”) provides a framework for Tribal governments to further develop their own regulations regarding how Tribal data, including health data, are shared and exchanged with external governments and partners. At its core, this resource is meant to be adapted by each Tribe to suit the Tribe’s specific needs, circumstances, customs, and traditions, with the goal of supporting how data, including health data, is shared to improve health outcomes in Indian Country.

The Model Code is designed to help ensure that Tribal Nations have a meaningful role in decisions about how data, particularly data related to their citizens and communities, is accessed and used. For example, this tool can support Tribes in identifying situations where data described as “de-identified” may still pose risks of re-identification for Tribal members. In such cases, the Model Code provides a framework for Tribes to assert their interests, request further discussion with external partners, and collaboratively determine an appropriate course of action. This process reinforces the principles of Tribal data sovereignty and strengthens the Tribe’s ability to govern its data in alignment with its values and priorities.

How to use the Model Tribal Data Sharing Code

1 Access the Model Code: [Click here](#)

2 Key Features and Approach

RESOURCE

The Model Code provides a framework for developing Tribal law related to the receiving of health data from other governments and the sharing of health data with other governments.

ADAPTABLE FORMAT

The Model Code employs a workbook-style format with overviews, examples, explanatory language, and model language.

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FLEXIBILITY

The Model Code is designed with flexibility and adaptability in mind – Tribes can shape it to fit the needs and priorities of their citizens and government.

COMPREHENSIVE

The Model Code is comprehensive and encompasses various chapters covering all aspects of data sharing from entering agreements to authorized parties for data sharing to Tribal obligations to protect data.

SUPPORTS SELF-DETERMINATION AND SOVEREIGNTY

At its core, the Model Code is designed to empower Tribal nations to access and use the health data of their citizen populations while protecting what each Tribe deems sacred.

3

Assessment and Internal Consultation

REVIEW THE MODEL CODE

Tribes should carefully examine the provisions of the Model Code to understand its framework and basic requirements to assess how they align with the Tribe's specific needs, priorities, and traditions.

IDENTIFY THE TRIBE'S PRIORITIES AND UNIQUE NEEDS

Tribes need to determine how the Tribe's unique circumstances, priorities, infrastructure, cultural practices, customs, traditions, and laws might necessitate adjustments or additions to the Model Code.

INTERNAL CONSULTATION AND COLLABORATION

Implementation will require engagement with the Tribal community according to the Tribe's customs, traditions, laws, and Constitution.

CONSULT WITH ELDERS AND COMMUNITY MEMBERS

Tribal Elders and community members should be consulted to ensure that the adopted code reflects cultural values and addresses community needs and concerns.



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Advisory Collaborative

ASPPH

Why is it important for Tribes to access public health data?

What rights does a Tribe have to its public health data?

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4 Adapt the Model Code

TAILOR THE CODE

The Tribe can now customize the Model Code to create a Tribe-specific version that reflects the Tribe's unique cultural values, customary practices, and input received from the community. Aside from the substantive tailoring, the Model Code contains language that can be adopted as-is or tailored to include the Tribe's preferred document template, terminology, tone, and writing style.

BUILD OUT TRIBAL-SPECIFIC PIECES OF CODE

The Model Code provides broad compliance with HIPAA and requires use of a data sharing or data use agreement to ensure Tribal jurisdiction. As appropriate and following consultation with legal counsel, the Tribe may include more information about Tribal processes or remedies.

5 Administrative Steps

ENACT THE FINAL CODE

Formalize the adopted code through the appropriate legal processes of the Tribe as defined by the Tribe's Constitution.

ESTABLISH A FRAMEWORK FOR IMPLEMENTATION:

The Tribe should develop the necessary administrative structure and processes to carry out and/or enforce the code, including identifying responsible Tribal staff.

6 Building Capacity and Training

TRAIN APPROPRIATE PERSONNEL

The Tribe should provide comprehensive training for Tribal staff who will be responsible for implementing and carrying out the requirements of the adopted code.

PROVIDE EDUCATION AND OUTREACH

Offer training and educational resources to community partners who might be on the receiving end of Tribal health data under the code.



Acknowledgement

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7 Collaboration and Coordination

COORDINATE WITH EXTERNAL AGENCIES

Work with the Tribe's local and state governments to establish relationships, share relevant information, and develop a data sharing or data use agreement to facilitate an approach to successfully implement the adopted code.

8 Seek Expert Assistance

ASPPH offers technical expertise to federally-recognized Tribes seeking to adopt the Model Code at no cost to Tribes, including technical assistance from Kaplan Kirsch LLP.

Tribes and tribal organizations may also seek independent legal expertise should they wish to make major changes to the Model Code and/or if there are unique or specific components that need to be incorporated.

9 Stay Updated

ASPPH will provide updates on relevant legal and policy developments, ensuring that the Model Code remains current and effective.

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Additional Resources

Additional Resources

Many organizations have an abundance of knowledge and resources for Tribes interested in issues of data sovereignty, data sharing, data governance, and more. The below list, complete with links, is not exhaustive.

[American Indian Health Commission](#)

[National Indian Health Board, Tribal Health Data and Resources](#)

[Northwest Portland Area Indian Health Board, NativeData](#)

[The Collaboratory for Indigenous Data Governance](#)

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

[Tribal Epidemiology Centers, The Importance of Data & Public Health Authority](#)

[The Udall Center for Studies in Public Policy's Native Nations Institute](#)

[Urban Indian Health Institute](#)

[U.S. Department of Health and Human Services Office of the Chief Data Officer, Tribal Data Homepage](#)

[U.S. Indigenous Data Sovereignty Network](#)