NativeDATA
A Data Sharing Resource for Native Peoples and Organizations

Building Successful Data Partnerships

Tribes and Native-serving organizations, including Tribal and urban Indian organizations and Tribal Epidemiology Centers (TECs), benefit from building strong data partnerships. Below are important things to consider when doing so.

Recognize Tribal Sovereignty

Whether you want to obtain or share health data, it is important to recognize Tribal sovereignty. Tribes are sovereign nations. Each Tribe has the power to govern their people, land, and resources how they see fit.[1,2]

Recognize Tribal Data Sovereignty

Tribes have the right to Tribal data sovereignty. Tribal data sovereignty is the right each Tribe has to control how their peoples' data is collected, kept, used, and destroyed.[3] Principles of Tribal (or Indigenous) data sovereignty can apply to data on American Indian and Alaska Native people off Tribal lands. Strong partnerships support Tribal sovereignty and data sovereignty.

Remember Tribes Have Public Health Authority Status

To make good decisions, Tribes need correct health data. Tribes have the power to protect the health, safety, and welfare of their citizens.[4] This is called public health authority. As sovereign nations, Tribes have the power to decide how they will use this authority.[5]

Know That Tribes Can Obtain Certain Protected Health Data

Due to Tribes' public health authority status under the Health Insurance Portability and Accountability Act (HIPAA),[6] HIPAA covered entities should share public health information when a Tribe requests it. This can be done without the HIPAA covered entity getting prior HIPAA authorization, as long as the Tribe plans on using the data for public health purposes.[7]

Recognize That TECs Have Public Health Authority Status

Under federal law, TECs have public health authority status under HIPAA. This means that TECs can obtain and use identifiable protected health information on behalf of the Tribes and urban Indian health organizations they serve.[8,9]

Get Connected With Knowledgeable Supports

If you are requesting data from a local, state, or federal agency, find Tribal liaisons or Tribal epidemiology points of contact. Ask these individuals for help. Often times in these agencies, non-Tribal-focused staff have little knowledge about the unique rights of Tribes and Native-serving organizations. Working with an individual who is knowledgeable can be very helpful. Also, there are many organizations and individuals who provide free guidance to Tribes and Native-serving organizations. Some of these supports are included here.

Offer Help To Non-Native Partners

It can be helpful to share resources on the unique rights of Tribes and Native-serving organizations with your partners. Consider sharing this resource to get them up to speed.

Come Prepared

The more you can plan before a first meeting, the better prepared you will be. Practice talking about your project and the areas where your goals and your potential partner's goals overlap. Being able to communicate about your timeline and how long it will take to get approvals, will help everyone.

Before meeting with a potential partner consider:

- What is your Tribal, organizational, and/or project mission?
- How are these connected to those of your potential partner?
- How would a data partnership benefit you both?
- If everything fell in place, when would you be ready?
- What does your timeline look like?
- What approvals and agreements do you need to get?
- How will you expect your partner to uphold Tribal sovereignty, Tribal data sovereignty, and the commitments you have to the people you serve?

Work To Build A Relationship That Is Long-Term

Respectful partnerships are balanced in terms of who has the power to make decisions, and whether resources are equitably shared between partners. Respectful partnerships benefit all parties. There is a long history of non-Native entities forming loose connections to Tribes and Native-serving organizations only to obtain data to further their own goals and interests. Working successfully with Tribes and Native-serving organizations should be a collaborative effort where partners make a long-term commitment to working together.

Non-Native partners must:

- Accept that Tribes and Native-serving organizations have the knowledge and expertise about what is best for their communities.
- Recognize that Tribes and Native-serving organizations hold the responsibility of ensuring the health and well-being of their communities.
- Make a commitment to respectfully learn from and about the Native communities they are partnering with.
- Recognize Tribes' and TEC's public health authority status.
- Ensure that partnerships provide capacity building, mentoring, training, and other supports that further Tribes' and Native-serving organizations' goals.

These are core steps universities and local, state, and federal agencies need to take in order to build trust with Tribal and Native-serving organizations. And it is the responsibility of Tribes and Native-serving organizations to cautiously consider their potential partners, establish strong data agreements that uphold Tribal sovereignty and Tribal data sovereignty, and continue to keep the needs and interests of the people they serve at the center of their work. Finally, it is the right of Tribes and Native-serving organizations to withdraw from agreements and partnerships that do not honor Tribal sovereignty, Tribal data sovereignty, and commitments that have been made.

Keep in mind

As partners in a data relationship, all parties have responsibilities to each another and the people they serve. It is the duty of local, state, federal, university, and other partners to learn about, respect, and support Tribal sovereignty, data sovereignty, and public health authority. And it is the role of Tribes and Native-serving organizations to know their rights and take steps to defend these rights.

Additional Resources

For Tribes and Native-serving entities:
- ASTHO - [Guide to Working with States for Tribal Leaders](#)
- ANSC - [Sample Code of Research Ethics](#)
- IPCB - [ATFE Protocol for Review of Environmental and Scientific Research Proposals](#)

For non-Native entities:
- NIHB - [Working with Tribes Training](#)
- University of Michigan - [Working Effectively with Tribal Governments](#)
- FEMA - [Building Partnerships with Tribal Governments](#)

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. Carroll SR, Rodriguez-Lonebear D, Martinez A. Indigenous Data Governance: Strategies from United States Native Nations. 2019. Data Science Journal, 18(31): 1-15.
4. 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/5930883f17bffcfab9debf8d/t/5ff396bd9d513670e3c76471/1609799358131/Tribes+are+Public+Health+Authorities+FINAL.pdf.
5. 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/tribalph-resource.pdf.
6. 45 CFR 164.501
7. Centers for Disease Control and Prevention. HIPAA Privacy Rule and Public Health. 2003. Morbidity and Mortality Weekly Report, 52; 1-12. Available at: https://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm.
8. James G. Hodge, Jr., Torrey Kauffman, Craig Jacques. Legal Issues concerning Identifiable Health Data Sharing between State/Local Public Health Authorities and Tribal Epidemiology Centers in Selected U.S. Jurisdictions: A report for the Council of State and Territorial Epidemiologists. 2011. Available at: http://www.cste2.org/webpdfs/LegalIssuesConcerningIdentifiableHealthDataSharingBetweenStateLocalPublicHealthAuthoritiesandTribalEpidemiologyCentersinSelectedUSJurisdictionsFINAL.pdf.
9. Centers for Disease Control and Prevention Public Health Law Program. Tribal Epidemiology Centers Designated as Public Health Authorities under the Health Insurance Portability and Accountability Act. 2015 Available at: https://www.cdc.gov/phlp/docs/tec-issuebrief.pdf.

NPAIHB
NativeDATA

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