NativeDATA
A Data Sharing Resource for
Native Peoples and Organizations

Tips for Obtaining Health Data

If you are a Tribe or Native-serving organization seeking data, you may be wondering about the process. Below are some useful things to consider.

Know What Data Exists

Tribes, counties, states, and the federal government regularly collect health data. Data is often stored in databases. To learn if the data you are looking for exists, read about common databases in Tribal public health.

Keep in mind

A common misconception among Tribes and Native-serving organizations is that county and state health departments collect Tribe-specific data. This is often not the case. Typically, data at the county or state level is collected by race/ethnicity. It may be possible to add a "Tribal Affiliation" category to data collection forms. However, there must be careful consideration about how this information could be used. Speak with your Tribal and/or organizational leaders, and with your county and state partners, about the benefits and risks of collecting these data. Advocate for this change if it is important and beneficial to Native communities.

Determine if You Can Accomplish Your Goals With a Public Use Dataset

You can access some health data without a data agreement. For example, the Centers for Disease Control and Prevention makes many public health datasets available through public use data files. Public use datasets do not have information that could cause privacy concerns for individuals. As such, they have fewer restrictions and requirements for data security. However, because these datasets have had information removed, they may not have the data you need to accomplish your goals. If that's the case, you will likely need to request a restricted use dataset through a data agreement.

Be Clear About How You Plan to Use the Data

When you reach out to someone to request data, they will want to know how you plan on using the data. Be sure to clearly describe your data request. If you are new to this process, consider completing this worksheet before making the ask.

Communicate Whether Data Will Be Used For Public Health Practice or Research

One common question you will be asked is whether you plan on using the data for 'public health practice' or for 'research'.

Public health practice includes when data is requested and used by a public health authority, like a Tribe, or their authorized partner to:

- Prevent or control disease or injury
- Improve the health of a specific population or group[1]

Generally, when data is used for public health practice, the potential benefits and risks from using the data impact the community and individuals who shared their information. With research, on the other hand, data are used to contribute to knowledge that will benefit those beyond the community and individuals who shared their information.[1,2]

Here is a table that can help you decide whether you plan on using data for public health practice or for research:

PUBLIC HEALTH PRACTICE VS RESEARCH

PUBLIC HEALTH PRACTICE	*RESEARCH*
Collection, use, and destruction of data is managed by a public health authority, like a Tribe or Tribal Epidemiology Center	Collection, use, and destruction of data is managed by a university, Tribe, or others experienced in doing research (such as Principal Investigators (PIs))
Primary goal is gathering insight to prevent or control disease or injury for a community or a specific group of people	Primary goal is to make general statements that contribute to science and the development of knowledge
Focused on improving the health of the public or a specific population or group	Focused on creating knowledge that can be applied more broadly
Benefits of data findings go mainly to the community and individuals who shared their information	Benefits of data findings go mainly to those beyond the community and individuals who shared their information

Source: Adapted from http://www.irb.emory.edu/forms/review/PH.html

If you are uncertain whether or not the work you are doing is considered public health practice or research, consult with an Institutional Review Board (IRB). This list of Indian Health Service and Tribal IRBs is a great starting place to find local contacts. However, note that there may be Tribal research committees or boards not listed. The HHS Office for Human Research Protections also provides in-depth information and contacts.

Keep in mind

If you are requesting data that will be used for human subjects research, your project will need oversight from an IRB. Data that are being used for public health practice typically do not need IRB oversight. However, your Tribe or organization may require you to submit your data collection and use plans to Tribal committees or boards.

Be Mindful of the Permissions or Approvals You Will Need

Depending on your Tribe's or organization's requirements, you may need multiple approvals to obtain data from an outside entity. These might include:

- Approval through a resolution from your Tribal council or governing board
- Approval from Tribal research review committees or boards
- Approval from specific departments within your Tribe or organization

It is important to know who your Tribe or organization requires to be involved with any data sharing process. Planning for the approval process can help your request to obtain data go smoothly.

Keep in mind

The process of obtaining data from an outside entity can be long. Make sure that you have a good understanding of both your and your partner's timelines.

Understand What Type of Data Agreement Is Needed

You can obtain data through different types of data agreements. If you are requesting data from an outside entity, ask if they have a template of an agreement that can be adapted. Your legal counsel, Tribal Epidemiology Center, and other decision-makers can help you with this.

Keep in mind

Tribes have the right to Tribal data sovereignty. This is the right to control the collection, ownership, and use of Tribal data. Principles of Tribal (or Indigenous) data sovereignty can apply to data on American Indian and Alaska Native people off Tribal lands.

Tribes and some Native-serving organizations also have public health authority status. Legitimate data sharing agreements and partnerships support Tribal sovereignty, data sovereignty, and public health authority.

Know What Costs Are Involved

Sometimes there are costs involved with obtaining data from local, state, or federal agencies. Ask your contact if they charge fees for providing data, and if any of these fees can be waived.

Got Questions?

Consider connecting with one of these data supports.

References:

1. Emory University Institutional Review Board. Public Health Practice. 2021 Available at: http://www.irb.emory.edu/forms/review/PH.html.
2. US Department of Health & Human Services Office of Human Research Protections. Human Subject Regulations Decision Charts: 2018 Requirements. 2020. Available at: https://www.hhs.gov/ohrp/regulations-and-policy decision-charts-2018/index.html.

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

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