



NativeDATA

A Data Sharing Resource for
Native Peoples and Organizations

Clearly Communicating About Data Sharing

Talking about obtaining or sharing health data can be challenging. Why? Data sharing has its own unique language. However, there are steps we can take to communicate more clearly. This document contains tips for clear communication around data sharing.

Use Plain Language

- Avoid confusing terms (“jargon”)
- Focus on using everyday language
- Give clear examples
- Use visuals whenever possible
- Avoid using many data points (this can be overwhelming for some)

Explain Why Data Sharing Matters

- Explain why data sharing matters to the specific individual and community you are working with or within
- Plainly describe the risks and benefits of participating in data sharing
- Discuss how obtaining or sharing data may help develop or expand relationships

Be Honest

- Clearly state your reasons for wanting to obtain or share data
 - Communities want and need to know what the interests of their collaborators are
- Describe everyone who is involved and what their aims are
- Provide realistic timeframes
- Describe realistic outcomes
- Be honest about what you know and don’t know

Describe How Data Will Be Kept Safe

- Explain the specifics of how data will be protected
 - Example: “They will be using a laptop to store the data. Both the laptop and data file will be protected by different passwords. They will keep the laptop behind three locked doors. They will not remove the laptop from this room.”
- Provide visuals that show the physical safeguards for the data
- Describe how confidentiality and/or non-disclosure policies will help protect the individuals and communities whose information is contained in the data
- Explain the specifics of who owns the data, and if the data is on loan or stewarded by an external partner
- Explain how the data will be safely and respectfully returned or destroyed once it has been used

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. Tribes and some Native-serving organizations, such as Tribal Epidemiology Centers, also have [public health authority](#) status. Legitimate [data agreements](#) and partnerships support Tribal sovereignty, data sovereignty, and public health authority.

Practice Makes Perfect

Practice explaining the topic to another person who doesn't know about data sharing and get their feedback before speaking with key decisionmakers.

Keep in mind

- Remember that the decisionmakers you speak with may have a different sense of urgency around the project you are discussing. Respect this. It may take months or years of [relationship building](#) before any data is shared or received.
- When you present to a Tribe's or Native-serving organization's leadership, make sure you have all the right people in the room. This includes individuals who can explain the technical aspects of [data protection and stewardship](#).
- This shows respect for Native communities and their leadership. It may also help move your project timeline forward more quickly.

The Takeaway

Talking about the project's purpose, safeguards, benefits and risks, and how data sharing may benefit the individual, community, and American Indian and Alaska Native people in general is an essential part of the data sharing process. Properly representing data sharing using plain language will help ensure that people can make good decisions that are in the best interest of those they serve.

Got Questions?

Consider connecting with one of these [data supports](#).

This Resource was Adapted From:

The National Cancer Institute's "Making Data Talk: a Workbook" - <https://www.cancer.gov/publications/health-communication/making-data-talk.pdf>



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

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