



NativeDATA

A Data Sharing Resource for
Native Peoples and Organizations

Is Requesting Data the Best Choice?

Tribes and Native-serving organizations, including Tribal and urban Indian organizations and Tribal Epidemiology Centers, have the power to obtain and share health data. This handout is designed to help you decide if requesting health data is the best choice for you and the people you serve. The cases below explore important questions to consider.

| QUESTIONS | CASE #1 | CASE #2 | CASE #3 |
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| What questions are you trying to answer with data? | A Tribal health planner wants to understand the top causes of death for Tribal members in her community. She also wants to know if there are differences for non-Tribal people living in counties near the Tribe's reservation. | A diabetes coordinator at an urban Indian health clinic is asked to improve a program to reduce commercial tobacco use among patients with diabetes. To evaluate the current program, the coordinator needs to know if patients with diabetes have increased, decreased, or remained consistent in their commercial tobacco use since joining the program. | A program manager at an inter-Tribal Council (a Tribal organization that serves a consortium of Tribes within a region) regularly receives requests from member Tribes for data on obesity, physical activity, and nutrition. The program manager often struggles to respond to these requests with the data available to them. |
| Who will benefit from the data you are seeking? | The planner believes the data will help the Tribe understand how to focus future prevention efforts. She also believes it will help support grant applications to fund health programs. | The coordinator believes the data will help patients with diabetes at the clinic who currently use commercial tobacco. He believes that data will also help the clinic improve its programming. | The manager believes that the Tribes may benefit from having data, so they can shape health programs to meet the needs of their communities. The data could also assist with grant writing and evaluating programs. |
| Who might be harmed by the data? | Family members of people who died could be harmed if they were identified and retraumatized or stigmatized. The Tribe could be harmed if the data were used to stereotype or stigmatize the community. If a data breach or loss occurred, the Tribe could lose the trust of community members. | Individual patients could be harmed if their data was taken or lost, or someone used the data to identify them. The clinic could be harmed if they were held responsible for the loss of data and for allowing others to access their patients' private health information. If a data breach or loss occurred, the clinic could lose the trust of its patients and community. | Tribal individuals could be harmed if they are able to be identified based on the data. Tribal communities could be harmed if data were used to stereotype or stigmatize them. If a data breach or loss occurred, the Council could lose the trust of its member Tribal communities. |

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| <p><i>Do the data you need to answer your questions exist in a Tribal, county, state, or federal database?</i></p> | <p>The health planner learns that death certificate data can answer questions about causes of death. However, these data don't have good information on Tribal affiliation, and there might be issues with accurately identifying deaths among American Indian/Alaska Native people in the state.</p> | <p>The coordinator learns that his clinic participates in the Indian Health Service's Diabetes Audit and that the audit includes information on commercial tobacco use among patients with diabetes. However, he doesn't feel confident about analyzing the data. After speaking with his supervisor, he contacts the Indian Health Service for support.</p> | <p>The program manager has explored the available data. While the state BRFSS collects useful information, the program manager learns from their state and federal contacts that the data can be unreliable for American Indian/Alaska Native people, especially at the local level.</p> |
| <p><i>If it exists, who has access to/control over the data you are seeking?</i></p> | <p>The planner learns that the state health department can share death certificate data.</p> | <p>The Indian Health Service provides the coordinator with information on upcoming trainings for the Diabetes Audit system. They also refer him to the Urban Indian Health Institute (a Tribal Epidemiology Center), that has access to the Audit data.</p> | <p>The state health departments in the Council's service area can release BRFSS data. However, due to confidentiality concerns, data broken down by specific race/ethnicity groups can't be released at the county-level.</p> |
| <p><i>What is your projected timeline?</i></p> | <p>The planner wants to complete the analysis in the next 2-3 months but has some flexibility.</p> | <p>The coordinator needs the data within two weeks.</p> | <p>The program manager doesn't have a specific timeline.</p> |
| <p><i>If data doesn't exist, what can be done?</i></p> | <p>The data exist, but there are some issues with accurately identifying deaths among Tribal members. The planner learns that linking the death certificate data with the Tribe's enrollment data might be a solution.</p> | <p>The data exist, and the coordinator learns that the Urban Indian Health Institute is able to create specific reports for his clinic's patient population.</p> | <p>The program manager determines there isn't a good source of data on obesity, physical activity, and nutrition for the Tribes they serve.</p> |
| <p><i>Is data sharing the right choice?</i></p> | <p>To weigh the benefits and potential risks, the planner speaks with her health leadership team. Together they decide that, with the Tribe's approval, they will pursue a data sharing agreement with the state.</p> | <p>The coordinator doesn't need to share or request data to answer his questions. The Urban Indian Health Institute has agreed to analyze his clinic's data.</p> | <p>The program manager speaks with their leadership and learns of resources for collecting Tribal BRFSS data. They decide to seek approval from member Tribes to collect data. In the meantime, they seek support from state, regional, and federal partners to make existing state-level BRFSS data more useful for their member Tribes.</p> |

Keep in mind

Tribes are sovereign nations. Tribes have the power to govern their people, land, and resources how they see fit. As sovereign nations, Tribes have the inherent right to data sovereignty. This means Tribes have control over how Tribal data is collected, managed, and used. Principles of Tribal (or Indigenous) data sovereignty may apply to data on American Indian and Alaska Native people off Tribal lands. To honor Tribes, Native-serving organizations, and American Indian and Alaska Native people, it is essential to uphold and defend [Tribal data sovereignty](#) and [public health authority](#).

Need Help?

There are several [data supports](#) who provide free advice to Tribes and Native-serving organizations.

Additional Resources

- Consider using this [worksheet](#) and this [handout](#) to help you prepare to make a formal request to obtain data from an outside entity.
- The Network for Public Health Law has a useful [checklist](#) on important data sharing questions.



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

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