



Issue Brief: Tribal Public Health Data Capacity and Infrastructure

Summary

The importance of Tribal public health data collection lies in its contribution to identifying and measuring trends over time to promote the overall health and well-being of Tribal communities. At present, while national-level data exists, it is almost always presented in aggregate (at times, to protect Tribal affiliation). This effectively erases community-level trends embedded within the data, including Tribal specific outcomes. Indian Health Service (IHS) data is a valuable source of Tribal health data but is limited and often outdated. State-level data is at least equally problematic, with rampant racial misclassification, variable quality, and the lack of data access without data-sharing partnerships. Investments into Tribal data capacity and infrastructure can empower Tribes and support the public health data systems needed to guide their public health efforts while respecting Tribal data sovereignty and culture.

Background

For centuries, Tribes have nurtured their own systems of health and well-being. In the present day, Tribes also integrate Western medicine and public health research. Data collection, maintenance, and analysis are cornerstones of public health frameworks and can help inform programs and policies. With the development of public health systems, there has been increased investment in health data. However, many current data systems do not consider Tribal needs or respect Tribal data ownership rights. AI/AN communities have long been mistreated and misrepresented by non-AI/AN data.

According to the 2018 U.S. Commission on Civil Rights Broken Promises report,

“Data on Native American and Native Hawaiians and Other Pacific Islander racial groups are often incomplete, inaccurate, old, or not tracked by the federal government. The best available data suggest sometimes extreme social and economic disparities between these communities and national averages. There is a critical need for more accurate and current data collection for these communities, including disaggregated data on American Indian, Alaska Native, and Native Hawaiian and Other Pacific Islander subpopulations, to improve the ability of federal, state, local, and Tribal governments to monitor conditions and make more informed policy and spending decisions.”

The primary source of national data on AI/AN health is the Indian Health Service (IHS), created in the mid-20th century to provide healthcare and related services to federally recognized Tribes. Authorized users can access aggregated, de-identified information via the National Data Warehouse. However, IHS data is limited to users of IHS and self-governing facilities, which may not capture information on Tribal citizens who are excluded from IHS scope or seek care in other health systems. Other non-AI/AN specific national surveys or initiatives, such as the Behavioral Risk Factors Surveillance System (BRFSS) survey and Healthy People 2030, contain information on AI/AN health status, but these immense collection efforts take several years to be published after collection. The health indicators used in national-level surveys may also not reflect AI/AN health priorities in their communities and may misclassify AI/AN people or include them in the “other” category, particularly when there is a small sample size.

Key Recommendations

- Increase funding for data collection, maintenance, and dissemination activities for Tribal Health Organizations (THO) and Tribal Epidemiology Centers (TEC). Increase funding for the recruitment, retention, and training of Tribal full-time employees in public health, specifically epidemiologists, statisticians, and public health informatics specialists.
- Increase recognition of Tribal data sovereignty and the status of both Tribes and TECs as public health authorities.
- Improve national and state-level engagement with Tribal partners and Tribal Consultation to expand data collection efforts and increase American Indian/Alaska Native (AI/AN) representation in the data.



Data Sharing Challenges and Solutions for Tribes

States and local health entities maintain or access a variety of data systems that contain health information on Tribal citizens, for instance, in public health departments. Like national data, AI/AN state data is often misclassified. As states do not have jurisdiction over Tribes, there are also data sharing challenges, and strong data sharing agreements are often necessary for Tribes to access their own communities' health data.

To address these challenges, Tribes may partner with Area Indian Health Boards and Tribal Epidemiology Centers (TECs) for data activities. These partnerships are helping to address gaps in Tribal data capacity due to decades of inadequate federal investment. 11 of the TECS support Tribes in a range of activities, including data collection and analysis, technical assistance, surveillance, and epidemiology.

Many Tribes also collect their own data, particularly for specific projects or initiatives undertaken in their communities. As many Tribes strengthen their public health systems, some also implement Community Health Assessments (CHAs), conduct routine surveillance, or collect environmental data. A 2016 study by the National Congress of American Indians (NCAI) assessing Tribal census data capacity indicated that half of the respondents have collected census surveys of Tribal citizens.

Characterizing Tribal Public Health Data Capacity through PHICCS

One source of national-level information about Tribal public health data infrastructure and data capacity is the Public Health in Indian Country Capacity Scan (PHICCS). PHICCS assessed the public health capacity of 134 respondents from 2018-2019. Findings highlighted that Tribal Health Organizations (THOs) prioritized health education and screening activities compared to data collection, epidemiology, and surveillance (DES) activities. For example, less than half the respondents collected morbidity data (41 percent) and injury data (42 percent), despite these being the most common DES services offered. Only 24 percent of respondents provided syndromic surveillance. Despite this, 58 percent of respondents considered data capacity and assessment skills as one of their top three organizational priorities. THO's also reported data-related workforce development needs, stating that epidemiologists, statisticians, and public health informatics specialists were the least funded and filled full-time employment positions.

What is PHICCS?

The Public Health in Indian Country Scan (PHICCS) is a national scan, to be conducted every three years by the National Indian Health Board, funded by the Centers for Disease Control and Prevention (CDC). The purpose of PHICCS is to assess the capacity of Tribal health and Tribal public health organizations for delivering public health services. This important tool helps Tribes, Tribal organizations, partners and policymakers better understand Tribal public health infrastructure and plan for future improvements.

Policy Implications

It is vital that, as public health authorities, Tribes have the ability and resources to access and utilize their health data to make decisions for their people. However, challenges with accessing useful, timely, and correct data at the national and state level remain a major barrier, particularly when partners do not understand Tribal data sovereignty. Furthermore, gaps in data infrastructure at the Tribal level can limit Tribe's ability to effectively collect and use data to serve their community.

Looking Ahead

Since their establishment, TECs have come to play an important role in capacity building and data collection efforts within Tribal nations. Tribes and TECs must receive data infrastructure funding, training, and recognition as public health authorities. Moving forward, there must also be increased and accessible training pathways for Tribal statisticians, epidemiologists, researchers, and data scientists to improve capacity. Additionally, Tribal data sovereignty must be prioritized as a component of overall self-determination. Tribes must have ownership of their data and indicators defined by them according to culture and health priorities. At the national and state level, these efforts can be supported by engaging Tribal partners to improve AI/AN participation in data collection efforts, preventing misclassification, and creating strong data-sharing partnerships that honor Tribal data sovereignty.