Native American public health officials say they are stuck in data blind spot

August 8 2024, by Jazmin Orozco Rodriguez, KFF Health News

Credit: CC0 Public Domain

It's not easy to make public health decisions without access to good data. And epidemiologists and public health workers for Native American communities say they're often in the dark because state and federal

agencies restrict their access to the latest numbers.

The 2010 reauthorization of the Indian Health Care Improvement Act gave tribal epidemiology centers public health authority and requires the federal Department of Health and Human Services to grant them access to and use of data and other protected health information that's regularly distributed to state and local officials. But tribal epidemiology center workers have told government investigators that's not often the case.

By July 2020, American Indians and Alaskan Natives had a COVID-19 infection rate 3½ times that of non-Hispanic whites. Problems accessing data predated the pandemic, but the alarming infection and death rates in Native American communities underscored the importance of making data-sharing easier, so tribal health leaders and epidemiologists have the information they need to make lifesaving decisions.

Tribal health officials have repeatedly said data denials impeded their responses to disease outbreaks, including slowing contact tracing during the pandemic and an ongoing syphilis outbreak in the Midwest and Southwest.

"We're being blinded," said Meghan Curry O'Connell, the chief public health officer for the Great Plains Tribal Leaders' Health Board and a citizen of the Cherokee Nation. The sharing of data has improved somewhat in recent years, she said, but not enough.

Federal investigators and tribal epidemiologists have documented a litany of obstacles keeping state and federal public health information from tribes, including confusion about data-sharing policies, inconsistent processes for requesting information, data that's of poor quality or outdated, and strict privacy rules for sensitive data on health issues like HIV and substance misuse.

Limiting the ability of tribes and tribal epidemiology centers to monitor and respond to public health issues makes historical health disparities difficult to address. Life expectancy among American Indians and Alaskan Natives is at least 5½ years shorter than the national average.

Sarah Shewbrooks and her colleagues at the Great Plains Tribal Epidemiology Center are among those who've found themselves blinded by bureaucratic walls. Shewbrooks said the data dearth was particularly evident during the COVID pandemic, when her team couldn't access public health data available to other public health workers in state and local agencies. Her team was forced to manually record positive cases and deaths in the 311 counties of North Dakota, South Dakota, Nebraska, and Iowa—the region the center serves.

Shewbrooks, director of the center's data-coordinating unit and its lead epidemiologist, estimates staffers spent more than a year's worth of their time during the pandemic scraping together their own datasets to steer information to tribal leaders making decisions about closing down reservations and asking residents to isolate at home.

She said the process was frustrating and stressful, especially since it robbed her team of hours they could've spent trying to save lives in the communities they serve. The tribes in their region were doing "incredible things," she said, by providing food and shelter for people who needed to quarantine.

"But they were having to do it all without being given real-time understanding of what's going on around them," Shewbrooks said.

Contact tracers who work for state governments cover Native American populations, but it's important to have people from within the community take the lead, Shewbrooks said. Tribal workers are better equipped to move around within their communities and meet people

where they are.

Shewbrooks said state contact tracers relied on calling and texting patients, which is often not the most effective method. Tribal members can be a hard-to-reach community for state workers whose protocol is to move on to the next case if they don't get a response.

"So many cases were just getting closed," Shewbrooks said.

In 2022, the Government Accountability Office published a report that confirmed concerns raised by tribal health officials, including at the Great Plains tribal epidemiology center. Federal investigators found that health officials working to address public health issues in Native American communities dealt with federal agencies lacking clear processes, policies, and guidelines for sharing data with tribal officials.

In one example, officials said that as of November 2021, 10 of the 12 tribal epidemiology centers in the U.S. had access to Centers for Disease Control and Prevention COVID data, but not all had full data. Some centers had access to case surveillance data that included information on positive cases, hospitalizations, and deaths. Only half said they also had access to COVID vaccination data from HHS.

The GAO report also found that staffers responding to data requests at HHS, the CDC, and the Indian Health Service did not consistently recognize tribal epidemiology centers as public health authorities. Center officials told federal investigators that they'd sometimes been asked to request data they needed as outside researchers or through the Freedom of Information Act.

The report recommended agencies make several corrections, including responding to tribal epidemiology centers as required by law and clarifying how agency staffers should handle requests from

epidemiology centers.

HHS officials agreed with all the recommendations. The agency consulted with tribal leaders in fall 2022 and, this year, published a draft policy that clarifies what data centers can access.

Some tribal leaders say the proposal is a step in the right direction but is incomplete. Jim Roberts, senior executive liaison in intergovernmental affairs at the Alaska Native Tribal Health Consortium, a nonprofit organization that provides care and advocacy for Alaskan tribes, said the GAO report focused on tribal epidemiology centers, which operate separately from tribal governments, each serving dozens of tribes divided into regions. The report left out tribes, which he said have a right to their data as sovereign nations.

HHS officials declined an interview request, but Samira Burns, principal deputy assistant secretary for public affairs, said the agency is reviewing feedback and recommendations it received from tribal leaders during consultation on the draft policy and will continue to consult with tribes before it's finalized.

Stronger federal policy on tribal data sharing would help with relationships with states, too, Roberts said. Tribal officials say problems they've experienced at the federal level are often worse in states, where laws might not recognize tribes or tribal epidemiology centers as authorities that can receive data.

At the Northwest Tribal Epidemiology Center, which works on behalf of tribes in Washington, Oregon, and Idaho, forging a data-use agreement with state governments in Washington and Oregon before the pandemic helped their response by providing immediate access to near real-time data on emergency room and other health care facility visits. The center's staff used this data to monitor for suspected COVID-related

visits that could be shared with tribal leaders.

It took seven months for the center to get access to COVID surveillance data from the CDC, said Sujata Joshi, director of the Northwest center's Improving Data and Enhancing Access project, and about nine months for HHS vaccination data after vaccinations became available. Even after getting the information, she said, there were concerns about its quality.

2024 KFF Health News. Distributed by Tribune Content Agency, LLC.

Citation: Native American public health officials say they are stuck in data blind spot (2024, August 8) retrieved 8 August 2024 from https://medicalxpress.com/news/2024-08-native-american-health-stuck.html

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.