



HEALTH CARE

American Indian tribes thwarted in efforts to get coronavirus data

The CDC has turned down tribal epidemiologists' requests for data that it's making freely available to states.



Team Rubicon volunteers work with local medical staff in the emergency room of the Kayenta Health Center on the Navajo reservation in Kayenta, Ariz. | Carolyn Kaster/AP Photo

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Federal and state health agencies are refusing to give Native American tribes



Centers for Disease Control and Prevention. | Jessica McGowan/Getty Images

Native American organizations have repeatedly run into roadblocks trying to get data from federal officials over the past month. The CDC has denied a series of requests from the nation's 12 tribal epidemiology centers for raw coronavirus data — even though state health departments are allowed to freely access the information.

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The tribal epidemiology centers were originally created to coordinate public health efforts between tribes and state and federal agencies. And under the

and organizations representing them access to data showing how the coronavirus is spreading around their lands, potentially widening health disparities and frustrating tribal leaders already ill-equipped to contain the pandemic.

The Centers for Disease Control and Prevention has turned down tribal epidemiologists' requests for data that it's making freely available to states. Authorities in Michigan and Massachusetts since early spring have also resisted handing over information on testing and confirmed cases, citing privacy concerns, and refused to strike agreements with tribes on contact tracing or other surveillance, eight tribal leaders and health experts told POLITICO. In some instances, officials questioned tribes' legal standing as sovereign entities.

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The communication gaps threaten to hinder efforts to track the virus within Native populations that are more prone to illness, disability and early death and have fragile health systems. Tribal authorities say without knowing who's sick and where, they can't impose lockdowns or other restrictions or organize contact tracing on tribal lands. The lack of data also is weighing on epidemiologists who track public health for the nearly three-quarters of Native Americans who live in urban areas and not on reservations.

“Because of the nature of the virus, which respects no physical boundaries, the ability to get the resources to where it's being disproportionately felt is a way to protect the broader population as well,” said Rep. Denny Heck (D-Wash.), a prominent lawmaker on American Indian affairs.

Affordable Care Act, the centers are considered public health authorities on a par with state health departments and federal agencies such as the CDC.

But Abigail Echo-Hawk, the director of the Urban Indian Health Institute, told POLITICO that the CDC has so far rebuffed the centers' requests — telling her only that the data is nonpublic.

“We struggle every single day to get the states, the counties and agencies like the CDC to actually comply with that,” Echo-Hawk said. “But they don’t recognize us.”

As of publication time, the CDC had not responded to a series of questions about the standoff first submitted to the agency on Wednesday.

The Urban Indian Health Institute is the main epidemiology center tracking public health for Native Americans who live off of reservations. Its staff is trying to access the CDC's National Electronic Disease Surveillance System and several other sets of coronavirus-related data that would aid their efforts to analyze the underlying health risks that could be putting American Indians and Alaska Natives at higher risk for coronavirus.

Echo-Hawk said that during a May 26 call on the issue, a member of the CDC's Case Surveillance Task Force at one point tried to explain to what epidemiology was to her team — an episode that she said illustrated the condescending attitude often directed at Native health organizations.

“It’s part of the systems of inequity in this country that I have to push, and we don’t always have the political power to push these large agencies to give us what we need,” Echo-Hawk said. “This is public health epidemiology — it's not research. The data is meant to understand the health of the community and address pressing public health concerns.”

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That has left UIHI and the other tribal epidemiology centers without access to core data about the coronavirus's spread nationwide, hampering efforts to track the disease across Native American populations and understand how and why it's killing tribal citizens in some areas at disproportionate rates.

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Indigenous people have a higher Covid-19 mortality rate than whites, Asians and Latinos, according to an [analysis](#) by APM Research Lab. And in hard-hit New Mexico, Native Americans account for nearly 60 percent of coronavirus deaths but just 8.8 percent of the population.

Last month, the Indian Health Service's chief medical officer, Michael Toedt, claimed on a press call that that his agency and the CDC had a mechanism to address data-sharing disputes between tribal organizations and departments of health. But a CDC spokesperson claimed to not know about any data-sharing

complications, and pointed to how the agency sent 15 experts to the Navajo Nation to assist with epidemiology and contact tracing.

“If you can’t measure [the coronavirus,] you can’t manage it,” said Stacy Bohlen, the executive director of the National Indian Health Board, which provides policy expertise to the 560 federally recognized Native American tribes. “It’s another chronic failing of what Indian people experience across the health system. We know it’s happening across the country.”

Tribal leaders have also hit roadblocks at the local level. The Bay Mills Indian Community in northern Michigan couldn't get Covid-19 data from surrounding Chippewa County after one of its members who worked as a guard at a local prison reported he contracted the virus. It took a showdown with the state before the tribal leaders won an agreement to share disease surveillance information with the state corrections department.

“It was a pretty heated exchange with the state, [we] said you guys are not an island,” said Bryan Newland, chair of the Bay Mills Indian Community. “Your officers clock out and go into the community, we need to know about this stuff.”

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Newland said Chippewa County continues to refuse to enter into an agreement with the tribe on surveillance and contact tracing. County officials didn't return repeated requests for comment.

"We had never taken the time to foster a working relationship with our local health department," Newland said. "There was never an occasion to give a lot of thought to our relationship and how to foster it."

State officials in Massachusetts this spring cited privacy concerns in turning away a request for coronavirus data from the Wampanoag Tribe of Gay Head/Aquinnah, which had asserted its right as a federally recognized nation and was trying to assist Covid-19 patients released from hospitals, said the tribe's chair, Cheryl Andrews-Maltais.

The tribe persisted, only to learn the state lumped Native American patients in with those from other racial categories. While it's since obtained a more thorough breakdown, the delay left the tribe flying blind, she said.

Massachusetts is one of at least two dozen states that either groups Native Americans into an "other" racial category as part of its coronavirus data, or doesn't track Native American case or death data at all. The group includes New York and New Jersey, which have among the largest urban concentrations of American Indians in the U.S.

Tribal leaders attribute the difficulties accessing data to a lack of knowledge of how Native American communities function and local authorities' lack of interest in working with them.

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Tribal organizations are supposed to deal directly with the federal government, because of longstanding federal trust obligations that established them as sovereign entities.

But the Trump administration has largely directed tribes to work with state and local officials on coronavirus issues, including obtaining medical supplies and coordinating response efforts.

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That's left the tribes trying to build new relationships during a public health crisis. The Indian Health Service — the main federal agency charged with caring for American Indians and Alaska Natives — does not keep data on hospitalizations or mortality rates for signs of emerging outbreaks, said Fawn Sharp, the president of the National Congress of American Indians.

Sharp enumerated those and other challenges last week at a briefing of the House Coronavirus Crisis Subcommittee, pointing to limited testing in Native American communities and the routine misclassification of Native Americans in local health data.

“The United States has chronically underfunded every sector of our health and socioeconomic life, creating a crisis in the 21st century that deeply affects our public health, our economy and our social life,” she said.

Yet over the course of the briefing's subsequent hour and a half of discussions, only a single lawmaker followed up to ask Sharp a question.

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