

# Tribal Health Equity Requires Tribal Data Equity

When the pandemic started, I was ready to jump in. American Indians and Alaska Natives were being diagnosed with COVID-19 at rates 3.5 times higher than non-Hispanic white persons. As a medical doctor with a master's degree in public health and epidemiology, I had studied and seen how to mitigate infectious disease and save lives. And as a tribal member with deep ties to South Dakota, I knew that implementing these proven public health measures would be challenging in our rural and medically underserved state. In September 2020, I received the chance of a lifetime and joined the Great Plains Tribal Epidemiology Center (GPTEC) to fight the pandemic in tribal communities in Iowa, Nebraska, North Dakota, and South Dakota. It was immediately clear that we needed to be aggressive in applying the toolset of epidemiology to disease prevention.

Take the classic public health practice of contact tracing in infectious diseases. Before this measure could save lives, GPTEC and our member tribal nations needed to know who had been diagnosed as infected—we needed data. Without this basic information, there was no way to make sure infected people and their contacts were isolating rather than spreading disease to more people. We couldn't even accurately follow tribal infection rates, which meant we lacked evidence needed to inform recommendations on mask use or school closures. By 2022, the devastating and disproportionate impact of COVID-19 on American Indian and Alaska Native (AI/AN) communities contributed to a 6.6-year drop in life expectancy from 2019 to 2021, leading to an average life expectancy for AI/AN people of 65.2 years—barely old enough to qualify for Medicare.

An effective COVID-19 response required access to data. In April 2020, the US Department of Health and Human Services launched HHS Protect, creating “a central source of data for the COVID-19 response ... to inform operations and decision-making.” However, data were not equally available or accessible. On January 21, 2021, his first full day in office, President Joe Biden issued Executive Order 13995, “Ensuring an Equitable Pandemic Response and Recovery.” It recognized that “the lack of complete data ... on COVID-19 infection, hospitalization, and mortality rates ... has further hampered efforts to ensure an equitable pandemic response.” That same month, the Government Accountability Office (GAO) began a performance audit that would find harmful gaps in Tribal Epidemiology Centers' (TECs') access to data, including COVID-19 data.

Established by Congress in 1992, the nation's dozen TECs are charged with monitoring and analyzing health data of AI/ANs and reducing glaring health disparities. In 2010, Congress reiterated this role, clearly stating that TECs were public health authorities under the Health Insurance Portability and Accountability Act, or HIPAA, and so, like other public health agencies, legal recipients of health information. However, having rights to the data has not meant that the TECs get them. “While TECs had access to some epidemiological data,” the March 2022 GAO report states, “officials from all 12 TECs we interviewed described challenges accessing other data from CDC [Centers for Disease Control and Prevention], IHS [Indian Health Service], or states.” Seven of the 12 TECs reported that officials at federal agencies did not seem to recognize their mandate to share data with TECs. The

IHS required one TEC to submit a Freedom of Information Act request to receive potentially lifesaving COVID-19 data, treating the center as a member of the general public rather than a public health authority. Such lack of access, TECs reported, could keep them from providing their communities with the information needed to make decisions.

I witnessed the impact of this inequitable access daily in my work at GPTEC. For the first two years of the pandemic, our team spent two to four hours every day collecting publicly available data from four state websites on the 311 counties in our jurisdiction. The work of copying and pasting was so time-consuming it required a dedicated new position. Despite all of that effort, the data available were inadequate. Race was often unspecified, preventing us from monitoring the COVID-19 rate in our AI/AN population. We also could not access identifiable information, such as names and addresses, for COVID-19 cases—information needed to assist tribal nations in essential contact tracing. Despite these limitations, we used available data to create a tribal COVID-19 dashboard and tribal-specific reports, often the only detailed information that TECs received to help make evidence-informed policy

Though state officials had identified the rise in syphilis cases in 2021, GPTEC and the tribal nations did not have access to the data, and thus could not launch a full response. Although we held community testing events and provided health education, we could not conduct contact tracing or provide tribal-specific syphilis reports. Our efforts to hammer out a data-sharing agreement with South Dakota's Department of Health took years, finally succeeding in March 2024, even though it was exactly the kind of exchange that Congress intended to facilitate by declaring TECs public health authorities.

Although this agreement represents a historic advancement for tribal public health in South Dakota, work still needs to be done. Tribes in our region outside of South Dakota do not regularly receive data from their state health departments. Even the South Dakota agreement is limited to certain types of data, requiring separate, one-off, and complex discussions about vaccination and vital records. At the federal level, our requests to the IHS for syphilis and other STI data remain unfulfilled, though it regularly reports this information to state health departments. We continue

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decisions. During the course of the pandemic, we gave advice on when to close businesses (and open them) and on when and where to wear masks, as well as on more fraught topics like closing reservations.

This is the role of public health: to monitor and help respond to threats like infectious disease and other causes of injury and ill health. The lack of data hinders our response in normal times and in public health emergencies. Resources that could be devoted to contact tracing or disease surveillance are drained away for the simple purpose of gaining access to data.

Many factors, including poverty, access to care, and geographic isolation, contribute to health disparities in AI/AN communities, but the lack of data thwarts any work to achieve health equity. For the past three years, my team has been struggling to manage a regional outbreak of syphilis. The South Dakota Department of Health reported 1,504 cases of syphilis in 2022, up from 56 in 2019. Though often asymptomatic, this sexually transmitted infection (STI) can lead to serious health problems. In pregnant individuals, it can cause stillbirths, miscarriages, low birth weight, and deformities. Syphilis can be cured with penicillin, but first we must find the people to treat.

to work with our state and federal partners to get the needed data, but the delays cause real harm.

Yes, TECs are requesting sensitive health information (formally classed as protected health information) such as substance use and STI status along with identifying information like names and addresses. Such information is to be released only when necessary and as laws allow. Officials do have an obligation to protect the privacy and security of the data; when confused about what the laws allow, they tend to err on the side of caution and limit data release. But this overcaution can cause harm.

In instances in which TECs have been able to access timely, robust, and specific data, they have achieved significant results. One TEC created an “injury atlas” analyzing causes of death and hospitalizations along with recommendations for prevention; others have created interactive dashboards on maternal and child health and other subjects. In April 2024, GPTEC and three South Dakota tribal nations brought CDC officials to our region to conduct a joint response to the syphilis and congenital syphilis epidemics. Using the data provided by South Dakota's health department, tribally led public health

teams (which included tribal staff, federal officials, and GPTEC staff) located and interviewed dozens of people with syphilis plus contacts and provided treatment to 62 individuals. That included six pregnant people, preventing potentially deadly congenital syphilis cases. This successful project all happened with just eight days of field work—and tribal access to appropriate data.

Federal or state agencies could not have achieved this result on their own. Tribal communities in our region are very rural; remote homes often lack conventional addresses and can be difficult to locate. Tribal public health workers have a deep knowledge of their communities that federal and state employees may lack. Tribes also have a broader conception of wellness and generally will provide more services than states, offering testing, treatment, and even wrap-around services such as isolation support and food. The successful intervention in South Dakota, which took nearly a year to organize, demonstrates what tribal nations can do when they have the right data. (Indeed, our CDC collaborators put together an inspiring presentation defining federal agencies' roles as facilitating data sharing and building tribal nations' capacity.) However, tribal nations and TECs are still burdened by the need to make repeated requests for data, each one requiring time- and resource-intensive negotiations for access.

The GAO report found that TECs could ease other agencies' fears of sharing data by developing "strong relationships" with officials at other agencies and so helping them gain trust in TEC staff's ability to safely and securely work with the data. But it should not come down to that. Such relationships can take years to build, if they can be built at all, and are inherently unstable. If one individual retires or changes jobs, the entire data-sharing relationship can collapse.

What's needed are strong affirmations that data should be shared. In January 2024, HHS released its first draft data access policy in response to the GAO report; the agency released a revision on September 3, 2024. The initial draft policy did not contain a clear presumption of access to identifiable HHS data for TECs, instead saying that data should be shared "when feasible or as appropriate." It also suggested that the only data to be provided to TECs was aggregate data, not "line-level" or identifiable data needed to perform contact tracing and other basic public health services. The more recent draft made significant changes based on tribal consultation discussions. While review and discussions are still ongoing, the current draft makes it clear that TECs are to receive both aggregate and individual data available to other public health authorities, without additional cost or process requirements to request or obtain data beyond what is expected of other public health authorities. This is the minimum standard required to *begin* to address data access equity. Tribal consultations

are scheduled for October 2024. Whatever the specific language of the final policy, to adequately address the needs of TECs and the communities we serve, HHS needs to provide immediate access to these data.

Federal agencies' failure to share data springs, in part, from an understandable fear of data breaches and privacy violations. GPTEC has industry-standard confidentiality and security measures in place to protect this sensitive information. One GPTEC employee even helped develop and manage the state's own data system. Unfortunately, continued concerns about TECs' ability to safely handle data can prevent information sharing and cause harm to community members.

Additionally, for many data holders, the mandate to keep data safe overrides the mandate to share. Workers reason that they are less likely to get in trouble if they stick with the status quo of not sharing. Or else they apply protocols worked out for researchers working with TECs and tribal nations, even though researchers' access to data is more restricted than what TECs have the right to receive as public health authorities. Also, although it is never explicitly stated, there can be bias against providing information to AI/AN organizations or governments. When TECs lack access to data, real people are harmed. Elders are hospitalized with the flu. Babies die from congenital syphilis. Young people commit suicide. Recognizing the harm data access barriers may lead to, federal agencies should create deliberate policies to enable sharing with tribal entities.

In medicine, data are shared freely between professionals who are working together to treat patients. Doctors do not have to develop years-long relationships with nurses to learn vital signs for a hospitalized patient. Pharmacists do not have to know the doctor who wrote the prescription in order to fill it. Everyone in the care community shares within the bounds of the law, and the default is cooperation, because that's what's needed for the health of the patient.

Public health should be no different. Our patients are communities, not single individuals. Data sharing should rely on something more than relationships between individuals who happen to work at different public health authorities covering some of the same people. There should be a culture and expectation for data to be shared, and an embrace of the legal and moral requirements to do so. To back that up, the CDC could tie data sharing to state funding for public health. And federal data modernization initiatives should be set up to make sure tribal nations and TECs are considered alongside states in terms of data access. Public health should look to medicine to see how teams work together and share vital information because we are all there for the same reason—to save lives.

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