

Roundtable Discussion with the Tribal Epidemiology Center Directors

COVID-19 Response in Indian Country



Attendee Question & Answer Session

Data

What more could you do for tribes on COVID-19 data if you were able to access more of that data?

If we had access to state surveillance systems, we would have access to real-time data, allowing us identify “clusters” on Tribal lands. With this, we could immediately offer assistance, assure American Indian and Alaska Native (AIAN) data is presented correctly, and identify misclassification of data. Many times, we are told that the number of AIAN peoples in the dataset is too small, thus AIAN peoples are omitted from reports. If this was corrected, we could potentially do small number analysis and provide a report or factsheet on the AIAN population for the state and/or county where programs are located.

How can we get more states to publish their AIAN COVID-19 data on their websites so the public can view?

This is dependent upon the data sharing agreements between Tribal nations and state/federal government. The release of Tribal-specific COVID-19 data without Tribal permission or knowledge can result in unintentional harm such as stigmatization of Tribal communities; racism, discrimination, and hostility toward Native people; fear of getting testing due to stigma, etc. Tribes have the right to govern the collection, ownership, and application of data. This still applies during the COVID-19 pandemic.

Can you publish a list of all the COVID-19 data related webpages on your TEC websites?

Each TEC has a website. You can find a wide variety of COVID-19 data, publications, reports and so forth on our websites. These websites can all be found on our collective TEC site, <https://tribalepicenters.org/>, where each TEC is represented and has contributed content. Please visit <https://tribalepicenters.org/tec-covid-19-resources/> to find direct links to all publicly available TEC COVID-related data, information, and resources.

What are you doing to encourage states to disaggregate COVID-19 data to share AIAN or tribal data? What can tribal nations do to help?

We respect Tribal sovereignty and will not conduct this work unless approved by Tribal Nation leadership. That being said, TECs work with Tribes to establish data use agreements so that disaggregated data that is available does not get released without their knowledge or permission; facilitate calls with states to explain the unique needs of Tribal Nations, TECs, and public health authorities; collaborate with partners to ensure that data provided is as granular as needed to ensure data for local and Tribal jurisdictions is available; and provide publications on best practices for data collection.

Is there value in data sharing rather than data hoarding?

Trust is a huge part of the equation in collecting data. TECs have been working in differing capacities with state health departments to establishing data sharing agreements. Some states have reached out to TECs, asking for guidance on how to collect data, analyze data, and how to present data. The Tribes, as sovereign nations, own their data. We steward it on their behalf and allow them to release it as they wish. Each Tribe speaks for themselves. Aggregate data is used for advocacy. We believe we are data stewards and the Tribes control the use and dissemination of the data.

What are the best practices for collecting AIAN data?

UIHI recently published a document on “Best Practices for American Indian and Alaska Native Data Collection,” addressing the incomplete, inaccurate, and unreliable standard data collection and analysis practices performed by federal, state, and local public health entities. It provides data collection best practices and recommendations that are grounded in and stem from Indigenous values and practices.

Relations with Indian Health Services (IHS)

How are Tribal Epidemiology Centers involved in reporting data to Indian Health Service (IHS) or confirming their numbers?

IHS data on COVID-19 cases have shown to be inaccurate. Underreporting and duplicate reporting are both concerns. TECs respond to this issues differently. Some contact each reported case to follow up on reports, as reports are not necessarily from Tribal members e.g., entries may be from staff or individuals that visited the clinic but are not living or associated with a Tribe. If errors are in reporting, TECs reach out to the IHS. The data we do have is as accurate as possible through multiple cross checks for accuracy.

Are state and local health departments sharing enough COVID-19 protected health information (PHI) with the TECs?

For the most part, states are not sharing this information. It depends on the state and the relationship we have with them. Some states have been receptive to sharing information with us through our data sharing agreements, while others have not.

People say IHS data on COVID-19 cases are inaccurate. Tribes or urban clinics are not required to submit data but it sounds like many do. In the absence of other data, what are the benefits and limitations of IHS COVID-19 case data?

IHS data on COVID-19 cases have shown to be inaccurate. Underreporting and duplicate reporting are both concerns. Other times reports are not necessarily from Tribal members. In these cases, individuals may have visited a clinic but are not living, or associated with, a Tribe. Some TECs are able to contact each case in their associated jurisdictions to follow up on reports. If there are errors in reporting, IHS can be reached and notified. The data TECs do have is as accurate as possible through multiple cross checks and epidemiologic data accuracy review.

Are Tribal health clinics (THCs) advocating for reporting on rates of COVID-19 cases and deaths?

Part of our role is to inform the populations we serve of the pros and cons of this type of reporting to IHS. Tribal Nations must balance reporting with Tribal sovereignty, and so, it must be a local decision. Though many Tribal Nations and urban facilities are reporting to their respective states.

Funding

How much federal funding did TECs receive from relief packages? How will the TECs use the funding?

Each TEC will be receiving variable funding for COVID-19 responses. These funds will then be delivered directly to Tribes and Tribal Health Programs. Each TEC may have different strategies for spending the funds dependent on their area needs. In some cases, funding is likely to be used for case and contact tracing strategies and building surveillance data systems, while in other areas, focus will be on virtual educational sessions, and support for environmental risk assessments. We strive to provide as many capacity building opportunities as requested.

Are you helping Tribes as they try to purchase personal protective equipment (PPE)?

TECs are responding in numerous ways to aid their communities with PPE deficits. For instances, TECs are providing funding awards to our Tribes to use for the COVID-19 public health response which includes PPE purchases; sourcing and purchasing PPE for area Tribal Nations; providing advice and trainings on PPE; advocating and coordinating for funding targeting supplies and PPE; and delivering donations of supplies.

If you could get one new resource in the next COVID-19 related legislation to help your efforts in aiding Tribes, what would that be?

Additional funding for TECs. Despite marked success and un-replicated services, TECs remain woefully underfunded. TECs receive an average award of \$340,000. Recent legislation has allowed for an unprecedented investment of \$24 million for TECs to address COVID-19, but long-term investments are still needed to address the chronic underfunding of TECs as public health authorities.

Comorbidity

While COVID-19 is overwhelming, what bandwidth or interest is there to characterize the intersection of COVID-19 with substance abuse, the opioid epidemic, other behavioral health issues, and health conditions?

Bandwidth differs among TECs. Many TECs have been working in areas related to behavioral health prior to the COVID-19 pandemic. Each TEC is working to adapt their ongoing programming during this time. Depending on the TEC, data dashboards share information on substance use disorders, suicidal visits to the emergency room during COVID-19, funeral resources, and others.

How are the Tribal Epi Centers coordinating with AIAN mental health centers and IHS to assist those struggling with anxiety, depression, recovery, and grief and loss issues related to passing of family members?

Many TECs provide resources on their websites; hold calls around these issues; and collaborate with other programs to provide behavioral health type of support to Tribes and Tribal health programs. Specific details can be found on the TEC websites or by contacting them by email.

Research

Researchers are planning and conducting research on new and existing diagnostic and antibody tests, and vaccines. If they want to conduct this research on AIAN peoples and/or with Tribes, what role do the Tribal Epidemiology Centers have in these efforts and/or what advice do you have for these researchers planning on conducting this research?

Tribes must be involved in research at every stage and make the decisions around how that research progresses. Tribal Epi Centers can advocate for Indigenous Data Sovereignty and Tribal Governance to ensure that Tribes are involved in research decisions to prevent harm and ensure benefit from this type of research. As sovereign nations, each Tribe will make decisions about entering into research for themselves. We can be a conduit for contact and have recommendations for best practices in conducting research in Indian Country.

Policy

How are your policy advocates using the data in advocacy work from the federal government, states, etc.? Or better: What are Tribes telling you their policy advocacy priorities are?

TECs draw from data they collect, as well as, local, state, and federal agencies when it is available to supplement. Data are used to advocate for legislative and administrative policy changes by demonstrating disparities in outcomes, highlighting successes, and projecting impacts. Specific policy priorities can vary widely by Tribe, Tribal organization, and urban Indian organization. Since the outbreak of COVID-19, Native advocates have gathered to develop joint policy priorities that impact all of Indian Country. [Check out these joint advocacy letters](#) for detailed policy priorities in the areas of infrastructure, governance, housing, health, education, nutrition, economic development, and employment. Overall, Tribes, Tribal organizations, and urban Indian organizations are calling for Congress to address the chronic underfunding of trust and treaty obligations to American Indian and Alaska Native people.

How widely do you think IHS, Tribal, and urban Indian health programs are taking your advice to not act on false negatives, while educating patients about negative COVID-19 tests? Is more education needed?

Health programs are hearing this message; however, this message needs to be internalized by all people, so that they aren't making personal decisions based on a negative result. Data regarding the Abbott test is changing quickly, depending on sampling technique. Some studies are showing a lower false negative rate than others. TECs have been providing education on the Abbott test and the problem with false negatives. Nonetheless, more education is needed on this topic, both for Tribal Health Programs and for the population in general.

Policy (continued)

TECs are public health authorities, but what does that mean?

Since the 2010 reauthorization of the Indian Health Care Improvement Act, TECs have been designated as public health authorities which authorizes TECs access to protected health information “for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions” (Id. § 164.512(b)(1)(i)). In addition to designating TECs as public health authorities, TECs are also allowed to access to data held by the Secretary of Health and Human Services, which includes data held by the IHS.

Staying safe now

What is the top thing that you can recommend that Tribes do now in your area during the COVID-19 pandemic to take action to protect their communities?

COVID-19 case investigations/contact tracing. Back to the basics. Social distancing, handwashing, etc. Social marketing campaigns. Primary prevention is key.

Are you worried about all the states that are reopening? Are they consulting with Tribes?

Each Tribal Nation and each state have varying relationships across different departments. We understand the economic pressures on states, tribes, and political leaders. TECs will be continuing to monitor data, and encourage contact tracing and testing.

What can we do, as private citizens, to support and lift TECs?

Please consider sharing TEC resources like factsheets and data through your advocacy efforts and social media.