



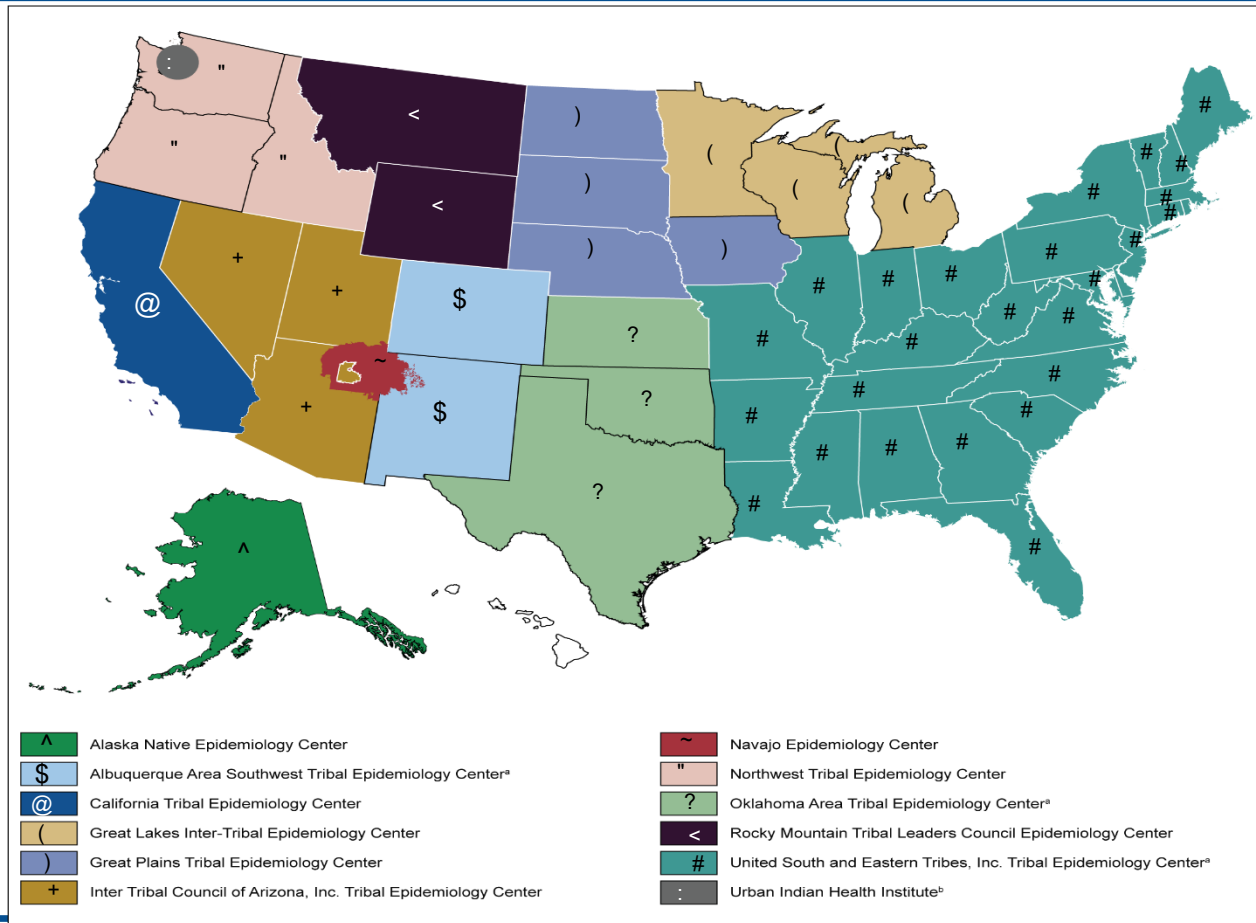
Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access

[GAO-22-104698](#)

Tribal Epidemiology Centers (TEC)

- Provide epidemiological functions and public health support for tribes, tribal organizations, and urban Indian communities.
 - Legislation enacted in 2010
 - Directed the Secretary of the Department of Health and Human Services (HHS) grant TECs access to HHS data. This includes data held by the Centers for Disease Control and Prevention (CDC) and the Indian Health Service (IHS).
 - Clarified that TECs are to be treated as public health authorities.
 - TECs have 7 core functions, which are specified by federal law.
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12 TECs Serving Tribes, Tribal Organizations, and Urban Indian Communities





Objectives, Scope, and Methodology

- 1) Describe TECs' access to and use of HHS and state epidemiological data.
- 2) Examine factors that have affected TECs' access to and use of HHS epidemiological data.

Methodology

- Reviewed documents, such as reports published by the 12 TECs, data sharing agreements, and CDC and IHS responses to TEC data requests.
 - Interviewed officials, including officials from CDC, IHS, and the 12 TECs.
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TECs' Access to Epidemiological Data Varied as of November 2021

- All TECs have access to data that HHS and states make publically available. For example
 - CDC's COVID-19 case data at the state and county levels
 - CDC's data on U.S. births, deaths, and cancer diagnoses
 - TEC officials told GAO they also had access to some additional data, but the specific data to which they had access varied. For example
 - Officials from 10 TECs told GAO they had access to CDC COVID-19 case data
 - Officials from 6 TECs told GAO they had access to CDC COVID-19 vaccination data
 - Officials from 9 TECs told GAO they had access to IHS patient registration and health encounter data
 - Officials from all 12 TECs described challenges accessing other data from CDC, IHS, or states.
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TECs Used Available Epidemiological Data to Conduct a Range of Analyses to Support Tribal Decision-Making

- Examples of TECs' analyses include
 - Identifying and tracking leading causes of mortality and morbidity for American Indian and Alaska Natives (AI/AN) in their service area.
 - Developing community health profiles outlining the health status and needs of AI/ANs in their service area.
 - Conducting surveillance on the spread of COVID-19 in their AI/AN communities.
 - TECs' analyses were conducted for and at the request of tribes, tribal organizations, urban Indian health programs, and IHS.
 - TEC officials told GAO their access to data influenced the analyses they were able to conduct.
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While HHS Has Some Systems to Share Data with TECs, Its Lack of Policies, Guidance, and Procedures Hinders Access

GAO found that four factors affected TECs' access to and use of HHS epidemiological data.

1. Data sharing systems and agreements have facilitated TECs' access to data.
 2. Lack of policies, guidance, and procedures has hindered TECs' access to data.
 3. Data quality and timeliness can affect TECs' use of data.
 4. TECs' capacity can affect their access to and use of data.
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Data Sharing Systems and Agreements Have Facilitated TECs' Access to Data

- The presence of data sharing systems like HHS Protect (HHS's central repository for COVID-19 data) and IHS's Epidemiology Data Mart (patient registration and encounter data) has facilitated TECs' access to data.
 - TECs have been unable to access data in some cases where such systems and agreements have not been established or do not meet the needs of the TECs.
 - CDC officials told us the agency does not have a system that enables it to readily share data on nationally notifiable diseases.
 - Not all TECs have been able to negotiate data sharing agreements.
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Lack of Policies, Guidance, and Procedures Hinders TECs' Access to Data

- HHS did not have a policy affirming TECs' authority to access HHS epidemiological data as of November 2021.
 - Some TECs faced a lack of clarity about their authority to access HHS data.
 - CDC and IHS had not developed guidance for TECs on how to submit data requests or established written agency procedures related to responding to those requests as of November 2021, according to agency officials.
 - CDC and IHS officials told GAO that they did not believe guidance or procedures related to TEC data access was needed, because TECs' requests were infrequent and officials believed they had successfully responded to TECs' needs.
 - Officials from 6 TECs told GAO that processes to request and obtain data were unclear and inconsistent. Further, officials from 7 TECs told GAO that they faced delays in receiving CDC or IHS data, making it difficult to adequately support tribal and community leaders.
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Data Quality and Timeliness Can Affect TECs' Use of Data

- Officials from 10 TECs told us that their ability to use CDC or IHS data was limited due to significant concerns about the data's quality or timeliness.
 - Officials from 8 TECs told us that HHS Protect included inaccurate and incomplete COVID-19 case surveillance data, including on patients' race and ethnicity and COVID-19 cases.
 - CDC officials told us that gaps in the data are likely to persist because the nation's public health system is decentralized and state reporting to CDC is voluntary.
 - Officials from 6 TECs reported that IHS Epidemiology Data Mart has limitations that prevent TECs from using it for certain analyses.
 - TECs do not have real-time access to these data and cannot use it for public health surveillance.
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TECs' Capacity Can Affect Their Access to and Use of Data

- Seeking access to data can require a significant investment of resources, according to some TEC officials we interviewed.
 - Officials from 9 TECs suggested that having better access to higher quality data would enable them to use their resources more efficiently—thereby expanding their capacity to serve their tribes—or to conduct more effective work for their tribes.
 - CDC and IHS have programs aimed at supporting and enhancing the capacity of all TECs to serve their tribes. These programs award funds and provide technical assistance to TECs.
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Recommendations to HHS, CDC, and IHS

HHS

- Develop a policy clarifying the HHS data that are to be made available to TECs as required by federal law.

CDC and IHS

- Develop written guidance for TECs on how to request data.
 - Guidance should include information on data available to TECs, how to request data, agency contacts, criteria the agency will use to review such requests, and time frames for responding to data requests.
 - Develop and document agency procedures on reviewing TEC requests for and making data available to TECs.
 - Procedures should include a description of data available to TECs, agency contacts, criteria for reviewing TEC data requests, time frames for reviewing TEC requests.
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