GAO Highlights

Highlights of GAO-22-104698, a report to congressional addressees

March 2022

TRIBAL EPIDEMIOLOGY CENTERS

HHS Actions Needed To Enhance Data Access

Why GAO Did This Study

AI/ANs have experienced long-standing problems accessing health care services and worse health outcomes than the general U.S. population, such as a life expectancy that is 5.5 years shorter than the U.S. average, according to IHS. To provide tribes with public health support, Congress required the establishment of TECs and, in 2010, authorized their access to HHS data. The COVID-19 pandemic highlighted the need to understand TECs' access to epidemiological data to help AI/AN communities prevent and control diseases.

The CARES Act includes a provision for GAO to report on its ongoing COVID-19 monitoring and oversight efforts. Also, GAO was asked to examine TECs' access to epidemiological data. This report (1) describes TECs' access to and use of epidemiological data, and (2) examines factors that have affected TECs' access to HHS epidemiological data. GAO reviewed HHS policies and documents and documentation of TECs' data requests. GAO also interviewed officials from CDC, IHS, and all 12 TECs.

What GAO Recommends

GAO is making five recommendations, including that HHS clarify the data it will make available to TECs as required by federal law; and that CDC and IHS develop guidance on how TECs should request data, and develop agency procedures on responding to such requests. HHS concurred with these recommendations.

View GAO-22-104698. For more information, contact Michelle B. Rosenberg at (202) 512-7114 or RosenbergM@gao.gov.

What GAO Found

Among the 12 tribal epidemiology centers (TEC), which are public health entities serving American Indian and Alaska Native (AI/AN) communities across the U.S., access to epidemiological data varied. Federal law authorizes TECs' access to data from the Department of Health and Human Services (HHS), including data from HHS's Centers for Disease Control and Prevention (CDC) and Indian Health Service (IHS), for a variety of public health purposes. However, according to TEC officials, access to non-public HHS data, such as CDC data on positive COVID-19 tests or IHS data on patient diagnosis codes, varied among TECs. TEC officials also described challenges accessing some CDC and IHS data, such as the inability to access certain CDC data on infectious diseases and other conditions. TECs used available epidemiological data to monitor the spread of COVID-19 and to conduct other analyses that support public health decision-making in AI/AN communities. However, TEC officials told GAO that their access to data influences the analyses they are able to conduct, and that a lack of access can limit their ability to provide AI/AN communities with meaningful information needed for decision-making.

The presence of CDC and IHS data sharing systems and agreements between the agencies and TECs have facilitated TECs' access to a range of epidemiological data, including on COVID-19 cases and the health of IHS facility patients. However, a number of factors have also hindered TEC access to HHS data, including

- **A lack of policies affirming TECs' authority to access HHS data**. Officials from seven of 12 TECs indicated that some CDC and IHS officials with whom they interacted when requesting data did not recognize that HHS is required by federal law to provide data in its possession to TECs. According to IHS and CDC officials, as of November 2021, HHS had not clarified the specific data that TECs are entitled to access under federal law.

- **A lack of guidance for TECs on how to request data, and agency procedures on how to respond to such requests**. CDC and IHS had not developed guidance for TECs on how to submit data requests or established written agency procedures for reviewing and responding to these requests as of November 2021, according to agency officials. CDC and IHS officials told GAO that they did not believe that guidance or procedures related to TECs' data access was needed, because TECs' requests were infrequent and they believed they had successfully responded to their needs. However, officials from six TECs told GAO that the process to request and obtain data was unclear and inconsistent within HHS. In addition, officials from seven TECs reported facing delays receiving CDC or IHS data, with some delays lasting over 1 year. According to TEC officials, these delays or limitations in accessing data made it difficult for them to adequately support tribal and community leaders, as they work to understand and address the health needs of AI/AN in their communities, including during the COVID-19 pandemic.