

Guidance for Federally Recognized Tribes and Tribal Epidemiology Centers on Requesting CDC Public Health Data

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I. Purpose

The Centers for Disease Control and Prevention (CDC) is providing this guidance to assist federally recognized tribes and Tribal Epidemiology Centers (TECs) in identifying and requesting tribal data from CDC.

This is the first iteration of this guidance and related materials, which are meant to provide a foundation for further CDC engagement with tribes, TECs, national organizations, urban Indian organizations, and others across the public health system on the collection, quality, analysis, and sharing of tribal data.

In addition, through the agency's [Data Modernization Initiative \(DMI\)](#), CDC is streamlining and improving data collection and sharing between the agency and its tribal and other public health partners; therefore, this guidance and approach will be improved over time, mainly through the DMI effort.

This guidance is supplemented by other tribal data resources and information provided on CDC's [Tribal Public Health Data site](#).

II. Guidance for Identifying and Accessing CDC Tribal Data

- Go to the [CDC Public Health Datasets and Access Guide for Tribes and Tribal Epidemiology Centers](#) to view a list of datasets and systems and CDC points of contact, and guidance on requesting and accessing the data.
- If you need assistance with identifying whether CDC has the data needed, requesting the data, or addressing an issue or concern with a current data request, fill out the general CDC [Tribal Public Health Data Request form](#). CDC's Office of Tribal Affairs and Strategic Alliances (OTASA) will receive the form and assist you.

III. Tribal Data Sharing Background

Status of Federally Recognized Tribes and TECs as Public Health Authorities

CDC recognizes the status of federally recognized tribes as sovereign governments, including as public health authorities. CDC also recognizes that the Indian Health Care Improvement Act (IHCIA) designated Tribal Epidemiology Centers (TECs) as public health



authorities for the purposes of the Health Insurance Portability and Accountability Act (HIPAA). The IHCIA allows TECs access to data held by the Secretary of the Department of Health and Human Services (HHS). IHCIA states that the HHS Secretary “shall grant to each epidemiology center . . . access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary.”

Need for Improved Public Health Data Collection, Sharing, and Use

In 2020, CDC launched a [Data Modernization Initiative \(DMI\)](#) to create modern, integrated, and real-time public health data and surveillance that can protect us from any health threat. This includes getting data where it needs to go to protect health. CDC needs to ensure the right policies, authorities, data use agreements, and relationships are in place to support modern data exchange. The [CDC Moving Forward](#) effort reinforces the importance of providing data for timely action to protect and improve health.

Tribes and TECs have requested through listening sessions, tribal consultations, and CDC/ATSDR Tribal Advisory Committee and HHS Secretary Tribal Advisory Committee engagements that CDC provide specific guidance on accessing tribal data generated or compiled from other sources by CDC. In addition, on March 4, 2022, the Government Accountability Office (GAO) released its report, [Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access](#). GAO provided recommendations for HHS, the Indian Health Service (IHS), and CDC. GAO’s recommendations for CDC are as follows:

- “The Director of CDC should develop written guidance for TECs on how to request data. Such guidance should include information on data potentially available to TECs, how to request data, agency contacts, criteria the agency will use to review such requests, and time frames for receiving an agency response to data requests. (Recommendation 2)”
- “The Director of CDC should develop and document agency procedures on reviewing TEC requests for and making data available to TECs. These procedures should include a description of data potentially available to TECs, agency contacts, criteria for reviewing TEC data requests, and timeframes for responding to TEC requests. (Recommendation 3)”

CDC’s responses to these recommendations over time are available on the [GAO report site](#).

Status of the Data Sharing Environment

- CDC surveillance and other data systems are created and managed by individual CDC programs. Therefore, CDC’s population health data are not centralized. CDC recognizes

that there is a need to make it easier to identify, request, and access data held by CDC, and the agency is working to address these needs.

- One aspect of CDC's Data Modernization Initiative is to address how to streamline and improve data collection and sharing between CDC and public health partners.
- State laws determine which diseases or conditions must be reported, who must report, and when, how, and what information must be included. States provide data to CDC on a voluntary basis. CDC does not have the authority to mandate that states provide CDC with data, nor what data they provide, nor how they provide it.
- Most data provided to CDC is de-identified data, so CDC may or may not have data with the specificity that tribes or TECs request or need. All parts of the public health system will need to work together to improve collection, quality, analysis, and sharing of data at every level.

How CDC Shares Data with Public Health Jurisdictions

- To help ensure broad access to public health information, CDC publishes statistical data in resources like [CDC WONDER](#), data.cdc.gov, and disease-specific atlases. These systems generally allow downloads of datasets with the statistics.
- For some CDC-held datasets, public-use datasets are available online. These datasets provide limited data elements to reduce the risk of disclosing personal or sensitive information. Many of these datasets have accompanying technical assistance materials for accessing, analyzing, and interpreting the data and some also offer visualization tools.
- Some datasets have restricted access. CDC provides information online on how to request access to those data. All public health authorities, including CDC researchers, must go through request and review processes before being provided access to restricted data.

Examples of What CDC Is Doing To Improve Data Sharing with Tribes and TECs

- CDC is working to ensure its programs are aware of tribes' and TECs' status as public health authorities and reinforcing data sharing expectations.
- CDC has released this first iteration of guidance for tribes and TECs for requesting CDC tribal data and has outlined internal CDC processes for receiving, tracking, and responding to requests.
- On June 27, 2022, CDC representatives met with the TEC Consortium to discuss TEC access to CDC data. Representatives from a number of CDC programs attended. CDC provided a short, high-level overview of the data systems writ large and then opened the floor for input and recommendations from the TECs. CDC is using the information received to inform its data efforts.

- During the 24th Biannual CDC/ATSDR Tribal Advisory Committee (TAC) Meeting on August 4, 2022, CDC received input and recommendations from the CDC/ATSDR TAC on tribal data issues. CDC is using that input to plan and implement CDC's data activities.
- On October 13 and 19, 2022, with HHS and IHS, CDC participated in an HHS tribal consultation seeking input on developing an HHS Tribal Data Sharing Policy that will cover all HHS operating divisions, including IHS and CDC. HHS expects to release a summary of the recommendations received and the agencies' preliminary responses to them in early January 2023.