Centers for Disease Control and Prevention (CDC)

Tribal Epidemiology Center Data Access Guidance

Sections:

1. Purpose

Under current law, Tribal Epidemiology Centers (TECs) exist to advance public health in Indian Country and are expected to work closely with the tribes, tribal organizations, and/or urban Indian organizations/communities in their respective area, including collaborating on data sharing and analysis, and ensuring tribal support for data requests and projects undertaken by the TEC. More specifically, the TEC statute enumerates seven core TEC functions which are intended to provide support to these communities. In addition, under the statute, TECs are treated as public health authorities (PHAs) for purposes of the Privacy Rule promulgated under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). *See* 25 U.S.C. §§ 1621m(b) and 1621m(e). It is therefore critical that TECs, acting in their capacities as PHAs, have timely access to appropriate data to support their public health activities.

To that end, the Centers for Disease Control and Prevention (CDC) strives to support TECs' data sharing and functional capacity to meet tribal and tribal organizational public health needs within their seven enumerated core functions, including but not limited to: data collection, disease surveillance, technical assistance, and response to tribal public health priorities.

The Department of Health and Human Services (HHS) Tribal Epidemiology Center Data Access Policy established an expectation that HHS divisions, including CDC, with data covered by the HHS policy, are to modify or develop implementation protocols for managing and responding to TECs' requests as they are acting in their capacities as PHAs for data in the division's custody and control. CDC provides this TEC Data Access Guidance document, in response to the HHS Policy, to reinforce data sharing expectations and assist TECs with identifying and requesting data within CDC's custody and control, consistent with applicable federal laws, regulations, and existing agreements with third parties.

This TEC Data Access Guidance document details the steps required for data requests, a list of potentially available datasets, and technical assistance resources.

2. Background

As noted above, the 2010 Congressional reauthorization of the Indian Health Care Improvement Act (IHCIA) formally acknowledged TECs as PHAs for purposes of HIPAA. As PHAs, TECs are authorized to access certain data within CDC's custody and control, to the extent permitted by applicable federal laws. Further, to the greatest extent possible, CDC will provide TECs with the same level of data access as other PHAs, without additional cost or process requirements to request or obtain data beyond what is expected of other PHAs.

In 2022, CDC's Office of Tribal Affairs and Strategic Alliances (OTASA) published *Guidance for Federally Recognized Tribes and Tribal Epidemiology Centers on Requesting CDC Public Health Data* to inform federally recognized tribes and TECs of the process for obtaining CDC public health data within their respective public health authorities. Following the publication, additional technical assistance resources became accessible on the CDC's Tribal Public Health webpage to support data sharing initiatives.

On December 6, 2024, HHS published the U.S. Department of Health and Human Services Tribal Epidemiology Center Data Access Policy, as referenced above, establishing HHS policy for data sharing protocols and governance with TECs.

This guidance document supersedes CDC's 2022 guidance, implementing updated protocols and guidance in alignment with the HHS TEC Data Access Policy.

3. Guidance for TECs to Request Data

CDC strives to streamline data sharing processes with TECs to promote more efficient accessibility, evaluation, and fulfillment of data requests. Below are procedures for TECs to follow when seeking access to data that CDC may have within its custody and control.

A. Publicly Available Datasets and Datasets of Interest

As a general matter, CDC intends to make data within the agency's custody and control available to the public to the extent practical and permitted by applicable federal law, regulations, and relevant federal agreements with third parties.

General public use datasets may be available online. TECs should refer to data.cdc.gov for more information on general CDC published datasets.

In addition, the CDC Public Health Datasets and Access Guide for Tribes and Tribal Epidemiology Centers resource document ("Resource Document") contains a list of existing potentially available datasets that may more likely be of interest to tribes and TEC activities related to tribes, given the nature of the data. The link to the Resource Document

is also located on the Tribal Data Homepage of the HHS Office of Chief Data Officer webpage under the CDC's Resource Column.

TECs interested in obtaining data from CDC identified on the Resource Document should refer to the data access process set out therein, which should provide information on how to directly obtain access to the corresponding data management system.

B. Data Request Procedure

If the TEC seeks data not otherwise listed on data.cdc.gov or the Resource Document, TECs may submit a request for data using the process outlined below.

1. Tribal Public Health Data Request Form

The CDC's Tribal Public Health Data Request Form is an electronic request form for requesting data that CDC may have within its custody and control but is not otherwise identified on data.cdc.gov or in the Resource Document.

CDC may request documentation from the requestor verifying that he or she is an authorized TEC representative. When submitting the data request, TECs should be as specific as possible in describing the type and scope of data the TEC is interested in. Additionally, if the TEC is requesting data as part of an emergency response, CDC encourages TECs to clearly state such and describe the nature of the emergency (see Section 3.B.3). Doing so will assist CDC with determining whether the agency has the requested data and how best to fulfill the request in a timely manner.

2. Timely Access Procedures

After a TEC has completed and submitted the Tribal Public Health Data Request Form, CDC's Office of Tribal Affairs and Strategic Alliances (OTASA) will acknowledge in writing receipt of the data request within 15 business days. OTASA will triage the data request to the relevant CDC program for response.

Within 90 calendar days of receiving the data request, CDC will inform the TEC whether the agency is able to grant the data request (i.e., confirm that the agency has the requested data within its custody and control and is able to provide the requested data to the requestor, in whole are in part) or must deny the data request. If CDC grants the data request in whole or in part, the relevant CDC program will provide a description of the steps necessary for the TEC to take to receive requested data (for example, completing a data use agreement or credentialing users for access to a data management system, if applicable). Any such requirements to complete a data use agreement, sign or acknowledge data access terms, credential users, or meet any other similar requirements will be consistent with applicable federal law, HHS TEC Data Access Policy, and CDC operational policy.

Once a data request has been acknowledged, CDC will respond to general TEC correspondence regarding the data request within 5 business days to help ensure timely access to approved data, consistent with HHS TEC Data Access Policy.

3. Emergency Data Requests

In the event of a public health emergency, CDC aims to expedite data requests where possible. As noted above, TECs should note in their data request form whether the request is being made as part of an emergency response. In doing so, the TEC should briefly describe the nature of the emergency to assist CDC with determining whether the agency has the requested data and how best to fulfill the request in an expedited manner.

All TEC requests for data that indicate a public health emergency situation will be prioritized for processing (for example, if there is another pending data request, the emergency data request will be processed first, if possible). Upon receipt of the emergency data request, CDC will inform the TEC in writing whether the agency is able to grant or deny the request as soon as practicable, but no later than within 15 calendar days of receipt. If the data request is granted, the relevant CDC program will provide a description of the steps necessary for the TEC to take to receive the data (for example, completing a data use agreement, or credentialing users for access to a data management system), if required by applicable federal law, HHS TEC Data Access Policy, or CDC operational policy. If the emergency data request is denied, CDC will inform the requestor in writing (see Section D).

C. Approved Data Requests

After CDC confirms if the requested data is within its custody and control, and can be shared, CDC will promptly provide such data to the extent permitted by federal laws, regulations, existing agreements with third parties, and consistent with CDC operational policy. CDC serves to uphold minimum data access parameters, data privacy and security requirements, and data use agreement (DUA) frameworks, as applicable and as described below, to ensure timely data access and secure data protections.

1. Minimum Data Access

Under HIPAA, HIPAA covered entities may share only minimum necessary data with the PHA for their public health activities and the entity is allowed to rely on a representation by the PHA that they are seeking minimum necessary data. In this context, TECs have been acknowledged as PHAs for purposes of HIPAA, but most CDC programs are not designated as HIPAA-covered entities. Therefore, most CDC programs will not rely on this representation.[1]

Instead, CDC programs, when receiving a data request from a TEC for data in CDC's custody and control, will consider the nature and scope of the request (e.g., emergency)

[1] 45 CFR Parts 160 and 164.

and the amount and type of information being sought. Further, consistent with the HHS TEC Data Access Policy, the programs will also consider any applicable federal laws and legal protections that apply to the agency and to the data (e.g., Certificates and Assurances of Confidentiality), or any third-party agreements that govern the use of the data and its sharing.

2. Data Privacy and Data Security

CDC will not provide data to any requestor, including TECs, where relevant and applicable privacy and security standards (e.g., for transmission of the data) cannot be met.

Data security requirements may vary based on the nature of the data being requested and, if applicable, which data management system the data may be stored within. Should any data security requirements apply to securely fulfill a data request, CDC will promptly notify the requestor within 90 calendar days of receipt of the data request.

Data privacy requirements ensure that the collection, management, use, analysis, disposal, and exchange of data are only authorized to the extent permitted by federal law, regulation, and federal agreements with third parties in place relevant to the underlying data source, including contracts, Certificates and Assurances of Confidentiality, and notices (e.g., privacy notices and consent agreements) with individuals from whom the data is collected. CDC acknowledges the legal permissions and data restrictions can be subject to variation by data type and dataset. Therefore, careful considerations and applications of data privacy afforded by federal laws and regulations, agreed upon terms in existing agreements, and reasonable technical constraints are factored into data activities with the implementation of this guidance.

Within data privacy, CDC acknowledges that individual consent for the data to be disclosed might be required and will be honored depending on the nature of the data and applicable federal laws, regulations, or agreements between CDC and third parties.

3. Data Use Agreements

Should CDC require, or the TEC request, a data use agreement, CDC encourages use of its data use agreement (DUA) template to support efficient processing. The CDC DUA template can be initiated by the CDC program that holds the requested data. The template includes standard, pre-approved provisions covering federal laws and other terms that CDC must adhere to, while also allowing the flexibility of data requestors to add terms, as needed. CDC will include appropriate details regarding data security protocols required, as applicable. Use of the template should be coordinated with CDC's Office of Public Health Data, Surveillance, and Technology (OPHDST) and, as necessary, the CDC Office of the General Counsel.

D. Denied Data Requests

CDC strives to make every effort to make data within its custody and control publicly available and to provide requested data to TECs. The provision of data and data access under the HHS TEC Data Access Policy and this CDC guidance document are subject to all applicable federal laws, regulations, existing agreements with third parties, reasonable technical constraints, and the availability of appropriations. In instances where CDC is unable to provide the specific data requested, CDC will work with the TEC to identify other datasets or information that can assist with satisfying the request. To the extent CDC is unable to fulfill the request, CDC will issue a written notice to the requestor with a reason for the denial.

E. CDC Points of Contact

For questions regarding tribal data requests or other tribal public health matters, please contact OTASA at tribalsupport@cdc.gov.

For questions regarding this guidance or other CDC data policy or data governance matters, please contact OPHDST at datapolicy@cdc.gov.

4. **Technical Assistance Resources**

Technical Assistance and Tools are provided on the Tribal Public Health Data webpage.

5. **References**

25 USC § 1621m, Epidemiology Centers

Health Insurance Portability and Accountability Act (HIPAA)

Indian Health Care Improvement Act

Public Health Authority and TECs

The Department of Health and Human Services (HHS) Tribal Epidemiology Center Data Access Policy

Tribal Affairs CDC Webpage

6. **Definitions** [2]

Data means information relevant to health and human services, including but not limited to information needed for public health purposes, that: is under the custody and control of HHS; can feasibly be disclosed to other government entities and public health authorities for use in activities advancing the health and wellbeing of Tribal members and related populations pursuant to and consistent with applicable law, regulation, and existing HHS

[2] Definitions are consistent with relevant terms defined in the HHS TEC Data Access Policy.

Division agreements; and is inclusive of data included in monitoring systems, delivery systems, protected health information (PHI) and other personally identifiable information (PII), including, unless specified otherwise, information at the individual and aggregate levels relevant to a specific Tribe.

Data Access means the act of providing data that is in HHS custody and control, including data maintained in monitoring systems and delivery systems, available for use by Tribes in their capacities as public health authorities and sovereign governments. Direct access to monitoring systems and delivery systems may only be provided when permitted by all applicable authorities.

Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law that, among other things, required HHS to adopt national standards to protect the privacy and security of certain health information. The implementing rules for these standards are the HIPAA Privacy, Security, Breach Notification, and Enforcement Rules (45 C.F.R. Parts 160 and 164).

Public Health Authority (PHA) means an agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate. *See* 45 C.F.R. § 164.501.

Tribal Epidemiology Center (TEC) means an epidemiology center established under Section 214 of the Indian Health Care Improvement Act, as codified at 25 U.S.C. § 1621m. A list of currently funded TECs is available at https://www.ihs.gov/epi/tecs/currently-funded-tec/. Per 25 U.S.C. § 1621m(b), TEC functions are specified as "(1) collect data relating to, and monitor progress made toward meeting, each of the health status objectives of the Service, the Indian tribes, tribal organizations, and urban Indian organizations in the Service area; (2) evaluate existing delivery systems, data systems, and other systems that impact the improvement of Indian health; (3) assist Indian tribes, tribal organizations, and urban Indian organizations in identifying highest-priority health status objectives and the services needed to achieve those objectives, based on epidemiological data; (4) make recommendations for the targeting of services needed by the populations served; (5) make recommendations to improve health care delivery systems for Indians and urban Indians; (6) provide requested technical assistance to Indian tribes, tribal organizations, and urban Indian organizations in the development of local health service priorities and incidence and prevalence rates of disease and other illness in the community; and (7) provide disease surveillance and assist Indian tribes, tribal organizations, and urban Indian communities to promote public health."

Tribe means an Indian or Alaska Native tribe, band, nation, pueblo, village, or community that the Secretary of the Interior acknowledges to exist as an Indian tribe pursuant to the Federally Recognized Indian Tribe List Act of 1994, 25 U.S.C. §§ 5130-31. Tribe is synonymous with tribal government.