Centers for Disease Control and Prevention (CDC)

Tribal Data Access Guidance

Sections:

1. Purpose

The Centers for Disease Control and Prevention (CDC) acknowledges federally recognized tribes as sovereign nations who exercise their rights of self-determination and self-governance over their members, territory, and resources, and who may also elect to exercise authority over public health matters impacting their tribal members, including emerging threats and other health-related needs in their communities. Agencies and authorities of a tribe responsible for public health matters as part of their official mandate, as well as those acting under a grant of authority from or contract with that public health agency, are public health authorities (PHAs) for purposes of the Privacy Rule promulgated under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). In their capacities as PHAs, it is critical that these agencies and authorities of a tribe have timely access to appropriate data for their public health activities.

CDC is dedicated to collaborating with federally recognized tribes on a government-to-government basis, firmly supporting and respecting their sovereignty and self-determination. This collaboration aims to enhance public health initiatives by ensuring tribes have access to data within CDC's custody and control that is necessary to effectively address the health needs and response activities of their communities.

The Department of Health and Human Services (HHS) Tribal 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 tribes' requests for data in the division's custody and control. CDC provides this Tribal Data Access Guidance document, in response to this HHS Policy, to reinforce data sharing expectations and to assist federally recognized tribes with identifying and requesting data within CDC's custody and control, consistent with applicable federal laws, regulations, and existing agreements with third parties.

The Tribal Data Access Guidance provides the steps required for data requests, a list of potentially available datasets, and technical assistance resources.

2. Background

In 1975, the Indian Self-Determination and Education Assistance Act (ISDEAA) was signed into law, affirming congressional support for the nation-to-nation relationship between the United States and federally recognized tribal nations.

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 tribal epidemiology centers (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 CDC's Tribal Public Health Data webpage to support data sharing initiatives.

On December 6, 2024, HHS published the HHS Tribal Data Access Policy., as referenced above, establishing HHS policy for data sharing protocols and governance with tribes.

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

3. Guidance for Federally Recognized Tribes to Request Data

CDC strives to streamline data sharing processes with federally recognized tribes, to promote more efficient accessibility, evaluation, and fulfillment of data requests. Below are procedures for tribes 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 laws, regulations, and relevant federal agreements with third parties.

General public use datasets may be available online. Tribes 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, 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.

Tribes 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 tribe seeks data not otherwise listed on data.cdc.gov or the Resource Document, tribes 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 representative of the tribe. When submitting the data request, tribes should be as specific as possible in describing the type and scope of data the tribe is interested in. Additionally, if the tribe is requesting data as a part of an emergency response, CDC encourages tribes 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 fulfil the request in a timely manner.

2. Timely Access Procedures

After a tribe has completed and submitted the Tribal Public Health Data Request Form, CDC's 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 tribe 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 or 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 tribe to take to receive the 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, the HHS Tribal Data Access Policy, and CDC operational policy.

Once a data request has been acknowledged, CDC will respond to general tribe correspondence regarding the data request within 5 business days to help ensure timely access to approved data, consistent with the HHS Tribal 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, tribes should note in their data request form whether the request is being made as part of an emergency response. In doing so, the tribe 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 tribe 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 tribe in writing whether the agency is able to grant or deny the request as soon as practicable, but no later than 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 tribe 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, the HHS Tribal 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 that the requested data is within its custody and control, 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 a 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, tribes, acting in their

capacities as PHAs, may have access to certain protected data for public health purposes. Most CDC programs are not designated as HIPAA-covered entities. Therefore, most CDC programs will not rely on this representation.

A tribe may also request datasets that can be made available to another government entity in furtherance of carrying out health and human services functions and promoting the health and well-being of its population. This includes, but is not limited to, datasets that contain aggregate data or individual-level data about members of the tribe, general datasets pertaining to public health events impacting the tribe, and datasets containing information about the health, public health, and human services delivery systems serving the tribe, to the extent permitted by federal laws, regulations, and agreements in place with the underlying data source, including contracts, Certificates of Confidentiality, and notices (e.g., privacy notices and consent agreements) with individuals from whom the data is collected.

When receiving a data request from a tribe, CDC will consider the nature of the request (e.g., emergency), the requestor's authority, the amount and type of information being sought, and the purpose of the request. Further, consistent with the HHS Tribal Data Access Policy, CDC 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. A subcomponent of the data that does not include private information might be shared with the tribe when fulfilling the full data request is not permitted.

2. Data Privacy and Data Security

CDC will not provide data to any requestor, including tribes, 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 and regulations 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 that 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 of 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 tribe 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 tribes. The provision of data and data access under the HHS Tribal 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 may be unable to provide the specific data requested, CDC will work with the tribe 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 Ch. 46: INDIAN SELF-DETERMINATION AND EDUCATION ASSISTANCE

Health Insurance Portability and Accountability Act (HIPAA)

Privacy Rule: HIPAA

US Department of Health and Human Services (HHS) Tribal Data Access Policy

CDC Tribal Affairs Webpage

6. Definitions [1]

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 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. For purposes of this guidance document, data access holds the same meaning as the term data sharing.

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

[1] Definitions are consistent with relevant terms as defined in the HHS Tribal Data Access Policy.

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, territory, or 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. Throughout this guidance document, Tribe is synonymous with Tribal government.