



Dear Tribal Leader:

In March 2022, the United States Government Accountability Office (GAO) issued a report entitled, [Tribal Epidemiology Centers, HHS Actions Needed to Enhance Data Access](#), where it found varied access to epidemiological data amongst the 12 tribal epidemiology centers (TECs) serving American Indians and Alaska Natives (AI/ANs). Included in the GAO report was a recommendation for the Department of Health and Human Services (HHS) to develop a policy clarifying the HHS data (including monitoring systems, delivery systems, and other protected health information) that are to be made available to TECs as required by federal law.

At the direction of the HHS Deputy Secretary, in September 2022, the Department initiated Tribal Consultation to seek input on developing an HHS TEC and Tribal data sharing policy. HHS used this input along with internal analysis to create the first draft of a Tribal and TEC Data Access Policy, which HHS released for feedback in January 2024. On February 6, 2024, HHS conducted a virtual Tribal Consultation to seek input on the new draft policy. Close to 229 participants joined the virtual consultation session and 18 written submissions were received through the comment period. Major themes raised during the Tribal Consultation included:

1. Concern over the inclusion of both tribes and TECs under one policy; desire to separate into two different policies.
2. Concerns over vague descriptions of which data is accessible to tribes and TECs; and a confusing, decentralized and administratively burdensome process for requesting datasets.
3. Lack of clarity on what categories of data HHS is able to disclose to Tribes, such as individual versus aggregate, Protected Health Information/Personally Identifiable Information, real-time, and substance use disorder data.
4. Desire for HHS to commit to minimum response deadlines to ensure timely resolution of data access requests, a pathway to appeal denials, and a right to a written reason for denials.
5. A range of perspectives on tribal right to notice or approval before their tribe-specific data is disclosed by HHS to TECs. Some indicated concerns about an opt-out policy lowering the completeness of datasets and ability of TECs to perform their duties, others expressed a preference for an opt-in policy or a more guaranteed opt-out process as better upholding tribal data sovereignty.
6. Desire for ongoing tribal input and HHS reporting on policy implementation once published.

Through the continued leadership of the Deputy Secretary's office, HHS has extensively revised the access policies from the January 2024 draft into two new policies: an HHS Tribal Data Access Policy and an HHS Tribal Epidemiology Center Data Access Policy. These documents reflect the input from prior consultation, as well as internal working group experts.

During the October 2022 and February 2024 consultations, HHS committed to consulting with tribes on the draft policy once it was complete, and the Department is now again acting on that promise. We ask that you please review the enclosed draft policies to offer your comments and recommendations to assist in the preparation of the final policy. Comments are welcome on all aspects of the draft policies. Major updates from the previous version include:

1. Separate policies regarding tribes and TECs.
2. Clarification on specific classes of available data.
3. Establishment of minimum timelines for response to requests and a guaranteed right to a written denial.
4. Creation of a new HHS Tribal Data Access Website that will:
  - a. List datasets available from each HHS Division that are of likely interest to tribes and TECs;
  - b. Provide information about data points of contact for each Division and how to request access to datasets; and
  - c. Offer an option to request help or report an issue with a data access request to HHS's Chief Data Officer.
5. Commitment to collaborating with tribes to develop an ongoing input and reporting process on data-related issues.

HHS's Tribal Data Access Website is now live at <https://cdo.hhs.gov/s/tribal-data>. We encourage you to bookmark this link and check it regularly for updates; we will be posting the final HHS Tribal and Tribal Epidemiology Center Data Access Policies, FAQs, and new Division-specific materials here as they are available. We also welcome input during this consultation about additional information or features you would like to see on this site.

As noted above, HHS received a range of perspectives on tribe-specific data disclosures from HHS to TECs during consultation. The HHS Office of General Counsel and an internal Division working group have worked diligently to identify a disclosure approach that is legally and operationally feasible, and responsive to the feedback we received. However, considering the divergent viewpoints reflected in the February consultation, and out of a desire not to delay the rest of the policies moving forward, we have removed this topic from the draft policies. HHS is interested in soliciting tribal feedback as part of this upcoming consultation on whether to establish a joint workgroup to resolve this outstanding issue.

We invite you to provide your input and feedback on the draft policies through one or both of the following methods:

**Virtual Consultation**

Date: October 1, 2024

Time: 3:00 – 5:00 PM EST

ZoomGov Registration:

<https://hhs.gov.zoomgov.com/meeting/register/vJIsde2grj8uGGIpr2dP29JGZRIFRw3MWc>

**Written Comments**

Written comments HHS Tribal Data Access Policy and HHS Tribal Epidemiology Center Data Access Policy are requested by October 31, 2024. Please send comments via one of the following methods:

- Email: [consultation@hhs.gov](mailto:consultation@hhs.gov)
- Subject Line: (please separate your comments by each draft)
  - HHS Tribal Data Access Policy
  - HHS TEC Data Access Policy
- Postal Mail: Bertha Alisia Guerrero, Director  
Office of Intergovernmental and External Affairs  
200 Independence Ave. SW  
Mail Stop: 620E  
Washington, DC 20201

Thank you for your continued partnership and support as we work to improve data access and health outcomes for tribal communities. If you have questions related to this consultation, please contact Devin Delrow, Principal Advisor for Tribal Affairs, by email at [TribalAffairs@hhs.gov](mailto:TribalAffairs@hhs.gov).

Sincerely,

/s/ Bertha Alisia Guerrero  
Director, Office of Intergovernmental and External Affairs  
U.S. Department of Health and Human Services

Enclosures:

1. Draft HHS Tribal Epidemiology Center Data Access Policy
2. Draft HHS Tribal Data Access Policy