



January 10, 2024

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 Secretary of 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.

In October 2022, HHS initiated Tribal Consultation to seek input on developing an HHS Tribal data sharing policy. Close to 200 participants joined the virtual consultation sessions, and 30 written submissions were received. Major themes raised in consultation included: honoring tribal sovereignty; maintaining data sovereignty; access parity; flexible policy terms; and the need for further tribal consultation as the policy developed. The attached draft HHS Tribal and Tribal Epidemiology Center Data Access Policy was created based on review of the extensive input received in consultation, as well as internal analyses of HHS Division data system considerations.

During the October 2022 consultation, HHS committed to consulting with tribes on the draft policy once it was complete, and the Department is now acting on that promise. We ask that you please review the enclosed draft policy to offer your comments and recommendations. Your input will assist in the preparation of the final policy. Comments are welcome on all aspects of the draft policy. We are also specifically requesting your feedback on the following:

- Which HHS Divisions would tribes and TECs anticipate they will seek data from under initial implementation of this policy? The policy will apply across the Department, however, not all Divisions yet have a full assessment of whether they have custody or control of data covered by this policy.
- Should other categories of data be included under the proposed definition of "Data," and are other elements in the proposed definition of "Tribe-Specific Data" recommended?
- Should "American Indian and Alaska Native" or another term identifying Native Americans be defined for the purposes of this policy? If so, which definition is recommended? Such definition would inform the identification of Tribal information in Division datasets and data systems.
- How, if at all, would tribes recommend the policy address tribal affiliation for the purposes of facilitating the identification of AI/AN data or data pertaining to a single tribe in HHS data sets and data systems? For instance, tribal enrollment versus self-identification of tribal affiliation.



- HHS recognizes both that TECs have access to certain data for their public health activities under 25 U.S.C. § 1621m *and* that tribes may elect not to work with their Area TEC or may have concerns about disclosures of tribe-specific data to that TEC. The draft policy includes language that would enable a tribe to request an opt-out of disclosures of tribe-specific data to an Area TEC. Are there different or additional parameters that tribes and TECs recommend?

We invite you to the following opportunities to provide your input and feedback on the draft policy.

Virtual Consultation:

Date: February 6, 2024

Time: 3:00 – 5:00 PM EST

Call-In: 669-254-5252

Meeting ID: 161-416-1119

ZoomGov Registration:

<https://www.zoomgov.com/meeting/register/vJisc-iurzorE5MWGjSDXfNG0spDpVXEm9o>

Written Comment Period:

We also invite tribes to share written feedback and recommendations on the draft HHS Tribal and Tribal Epidemiology Center Data Access Policy. Written comments are requested by March 5, 2024. Please send comments via one of the following methods:

- Email: consultation@hhs.gov
- Subject Line: HHS Tribal Data Policy
- Postal Mail: Acting Director Jess Smith
Office of Intergovernmental and External Affairs
Hubert Humphrey Building
200 Independence Ave. SW
Mail Stop: 620E
Washington, DC 20201

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

Sincerely,

/s/ Jess Smith
Jess Smith, Acting Director
Office of Intergovernmental and External Affairs
U.S. Department of Health and Human Services

Enclosure: Draft HHS Tribal and Tribal Epidemiology Center Data Access Policy