



September 28, 2022

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/AN). Federal law authorizes TEC access to data from the U.S. Department of Health and Human Services (HHS), including data from HHS's Centers for Disease Control and Prevention (CDC) and Indian Health Service (IHS), for a variety of public health purposes. However, the GAO found that access to non-public HHS data, such as CDC data on positive COVID-19 tests or IHS data on patient diagnosis codes, varied among TECs. In the report, TEC representatives described challenges accessing some CDC and IHS data, including the inability to access certain CDC data on infectious diseases and other conditions.

In response, the GAO recommended five Executive Actions, of which HHS concurred, stating that it will take steps to develop a policy clarifying the data that are to be made available to TECs. The five Executive Actions are listed below:

- The Secretary of HHS should 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.
- 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.
- 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 time frames for responding to TEC requests.
- The Director of IHS should develop written guidance for TECs on how to request data. Such guidance should include information on the data 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.
- The Director of IHS should develop and document agency procedures on reviewing TEC requests for and making data available to TECs. These procedures should include a description of the data available to TECs, agency contacts, criteria for reviewing TEC data requests, and time frames for responding to TEC requests.

HHS's progress toward addressing these recommendations is available on the GAO report website provided above.



HHS acknowledges and respects the importance of tribal sovereignty in the collection, management, and the use of tribal data. Therefore we are initiating Tribal Consultation to seek input on developing an HHS Tribal Data Sharing Policy. Input from tribes is essential to inform the development of any new policy and to build relationships of trust between HHS, TECs, and tribal communities. In developing this new policy, we are requesting your feedback on the following questions:

1. What kinds of data-related support from HHS agencies do tribes need?
2. What technical assistance do tribes need to best support their data access and data quality needs?
3. How have barriers to data access affected your efforts to address public health challenges?
4. What are some examples of the type of support that a TEC provides to your public health activities?
5. To what extent should HHS share tribal members' health information with TECs to facilitate their public health activities?
6. What legal/policy barriers, have you encountered at the state or local level for accessing data held by those jurisdictions?
7. If tribal affiliation is included in data collection, what are your recommendations for collecting and sharing that type of information?
8. How can HHS agencies improve quality and utility of AI/AN health data?

These questions are only intended as a starting point to facilitate a robust conversation. We invite you to the following opportunities to provide your input and feedback.

Virtual Events

October 13, 2022

2:00 – 3:00 PM ET

<https://www.zoomgov.com/meeting/register/vJItD-CuqjIrHeR9IA3muLCRTdWIXffblrQ>

October 19, 2022

3:00 – 4:00 PM ET

<https://www.zoomgov.com/meeting/register/vJItD-CuqjIrHeR9IA3muLCRTdWIXffblrQ>

We also invite tribes to share written feedback and recommendations to us at consultation@hhs.gov by October 28, 2022. Thank you for your continued partnership and support as we work to improve data access and health outcomes for tribal nations.

Sincerely,

Marvin Figueroa,

Director, Office of Intergovernmental and External Affairs