



HHS TRIBAL CONSULTATION ON GAO REPORT
"TRIBAL EPIDEMIOLOGY CENTERS: HHS ACTIONS NEEDED TO ENHANCE DATA ACCESS"
SUMMARY REPORT

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INTRODUCTION:

On September 28, 2022, the Department of Health and Human Services (HHS) initiated Tribal Consultation pursuant to [Dear Tribal Leader Letter](#) on the United States Government Accountability Office (GAO) issued 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). HHS sought input on developing an HHS Tribal Data Sharing Policy. Responses could be received in two ways, through: (1) attendance at one of two virtual consultation sessions held on October 13 and 19, 2022; and/or (2) by providing written comments to HHS by October 28, 2022.

Close to 200 participants joined the virtual consultation sessions, and 30 written submissions were received. Tribal leaders were invited to provide open feedback in relation to the development of an HHS Tribal Data Sharing Policy. To facilitate the consultation, HHS posed seven guiding questions as a starting point for a robust conversation around data challenges and opportunities. This memorandum summarizes the common concerns and themes expressed by Tribal leaders in the virtual sessions and through written comments.

CONSULTATION BACKGROUND:

In March 2022, the GAO issued its report on "Tribal Epidemiology Centers, HHS Actions Needed to Enhance Data Access." Federal law authorizes TEC access to HHS data for public health purposes, including data from HHS's Centers for Disease Control and Prevention (CDC) and Indian Health Service (IHS). 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 Tribal Epidemiology Centers (TECs). In the GAO report, TEC representatives described challenges in accessing some CDC and IHS data, such as the inability to access certain CDC data on infectious diseases and other conditions.

GAO recommended five Executive Actions for the HHS Secretary, CDC, and IHS. HHS concurred with the recommendations, stating that it will take steps to develop a policy clarifying the data that are to be made available to TECs. Through the consultation, HHS sought recommendations and feedback on developing an HHS Tribal Data Sharing Policy that will be inclusive of Tribes and TECs and the comments that were received are the subject of this report.

HHS ACTIONS RELATED TO GAO REPORT:

HHS is acting to timely address all five of the GAO's recommendations. The status of the response actions of the HHS Secretary, CDC, and IHS is publicly viewable through the GAO at: <https://www.gao.gov/products/gao-22-104698>. The status of each of the five recommendations is currently open and pending further actions by HHS, CDC, and IHS.

HHS has conducted Tribal consultation on the development of an HHS Tribal Data Sharing Policy (*see "Consultation Background"*). HHS anticipates completing a draft policy in late winter of 2023 and a final policy in the late spring of 2023. The policy will clarify the data that are to be made available to Tribes and TECs.

CDC is working to improve agency procedures on reviewing TEC requests for data and making data available to TECs. As part of this process, CDC reported establishing a network of CDC points of contact for planning and implementing these procedures, and reviewing current CDC data policies to see what, if anything, should be updated. To fully implement this recommendation, CDC must develop procedures on reviewing TEC requests for and making data available to TECs.

CDC is expecting to launch its new Tribal Public Health Data web site by the end of December 2022. It will contain the first iteration of the guidance related to CDC data sets and systems and how to access them, including restricted data. This is first iteration of the guidance and related materials and is meant to provide a foundation for more engagement of CDC with Tribes, TECs, national organizations, urban Indian organizations, and others across the public health system on collection, quality, analysis, and sharing of Tribal data.

IHS has begun developing a policy for sharing data with TECs. In developing this policy, IHS reported assessing the breadth of existing data sharing practices with TECs, reviewed data use agreements currently in place, and evaluated the internal review and approval procedures used to respond to TEC data requests. Based on these initial assessments, IHS has begun developing new national policy governing IHS data sharing practices with TECs to clarify procedures while seeking to streamline efficiency and improve consistency in TECs' access to appropriate IHS data. Policy development will require careful consideration of input from various stakeholders, both internal and external to the IHS, to yield a policy that affects meaningful improvements to meet the needs of both the IHS and TECs. As this policy-building effort matures, iterative internal review and input from leaders at varying levels, including IHS Area Directors and key field staff, will inform policy alignment with local priorities to ensure relevancy and buy-in. IHS anticipates completing its policy and guidance for TECs on how to request data by April 2023.

In parallel with the above actions, the IHS continues routine, ongoing distribution of Epidemiology Data Mart data to TECs, with the most recent data sets distributed to participating TECs in November 2022.

CONSULTATION THEMES AND RECOMMENDATIONS:

Common Themes:

Tribal Sovereignty and Data Sovereignty. Nearly all Tribes and Tribal organizations that participated discussed the vital importance of Tribal sovereignty, including data sovereignty, to any future policy. Tribal leaders stressed the responsibility of Tribal governments as public health authorities (PHAs) in protecting their citizens. They stated that Tribes must own, control, and regulate the collection of, access to, and use of any Tribal data. Many respondents described how Tribal sovereignty in this area has not been upheld, and expressed the desire for this to be rectified by codifying respect for Tribal data sovereignty in the new policy. Many recommendations were received calling for the policy to include a discrete, express Tribal authorization requirement for any federal, state, or other entity, including TECs, to collect, access, use, or publish Tribal data. Many respondents stated the type of Tribal authorization to convey such approval should be left open to each Tribe to decide what would work best for their circumstances. Examples included: a Tribal council resolution, limited data use agreement, institutional review board, or other mechanism. One respondent cautioned that, while Tribal authorization is a necessity, it must be balanced with timeliness considerations to avoid hindering real-time responses to public health issues. Individual time-limited data sharing resolutions were thus discouraged.

Several respondents pointed out that Tribes have varying capacities to complete epidemiology work within their respective Tribal health departments. They stated that "[w]hether a tribe chooses to perform these functions on our own behalf or if tribes choose to delegate their work to their area [TECs], is a tribe's inherent sovereign authority." Where delegation occurs, Tribal leaders stressed the need to honor TEC PHA as an extension of Tribal sovereignty.

Implement Existing Law. Many commenters exhorted HHS to "follow existing federal law and provide TECs with the data tribes need to protect our members" in accordance with their PHA under the Health Insurance Portability and Accountability Act (HIPAA) and the 2010 amendments to the Indian Health Care Improvement Act (IHCA). The amendments mandate that the HHS Secretary provide TECs with "access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary."¹ Respondents collectively discouraged any policy language that would restrict data access, whether directly or indirectly, for Tribes and TECs.

Parity of Access without Additional Burdens or Conditions. Tribal leaders stated that, as a minimum, Tribes and TECs should be provided with the same level of data access as other PHAs, without the imposition of any additional conditions or administrative burdens. Many commenters

¹ 25 U.S.C. § 1621m.

noted that this may include access to non-Tribal member data. Respondents also want parity of access to include full eligibility for Tribes and TECs in any funding opportunities made available to other PHAs. Commenters stated that HHS could use the system it already has in place to share data with other PHAs to now share data with Tribes and TECs.

Flexible and Broad Coverage. We received many recommendations that the HHS Tribal Data Sharing Policy "be broad and flexible." Many commenters recommended all HHS agencies, not only the CDC and IHS, establish clear policies and procedures for protecting Tribal data sovereignty, including Tribal control of their own data, and ensuring timely data access for Tribes and TECs. This would be consistent with and facilitate the implementation of the common recommendation that Tribes have access to all HHS data systems, as well as state and local data systems.

Consultation. Several respondents raised comments about the consultation. A small number expressed concern about the intended scope and impact of the current consultation, specifically concern that the policy would restrict Tribal or TEC access or call into question the utility of TECs as public health entities. HHS also received at least one comment calling for the current consultation to "slow down" for greater participation, and more than one comment calling for additional consultation on the specific issue of TEC data access. A handful of respondents recommended that HHS circulate the draft HHS Tribal Data Sharing Policy for consultation. Another respondent suggested that data sharing become a standing agenda item for HHS Tribal advisory bodies across agencies.

Question #1: What kinds of data-related support from HHS agencies do tribes need?

Equitable and Responsive Data Exchanges. A high number of comments stated that any data collected from Tribes should also be made available directly back to Tribes and TECs. The lack of equitable exchange of information with systems into which Tribes provide data but do not receive responses was frequently discussed. Tribal leaders stressed the need to access and receive their Tribal information from these systems to address emerging threats and ongoing public health situations in their communities, as well as to inform decision-making around regional and national AI/AN health issues.

Clear Definitions. Several commenters asked HHS to clarify how it will define "data" for the purposes of the policy. Tribal respondents urged a broad definition of "data" that should be inclusive of monitoring systems, grant reporting, delivery systems, and other protected health information (PHI).

User Accessibility. One commenter recommended IHS develop a process for Tribal programs to remotely access data from VPNs for home workers, as well as develop a data dashboard to facilitate data retrieval and analysis for "quality improvement, population health, public health, and overall clinic operations." Another suggested that a simple, searchable electronic data inventory be developed that would cover all available data sources within the HHS.

Other Comments. Additional comments that HHS received in response to this question included, but are not limited to, the following:

- Streamlined, secure, direct delivery of data to Tribes and TECs.
- Periodic evaluation of data delivery and associated processes.
- Assist Tribes in data-capacity building and IT infrastructure development and maintenance for onsite data management and analytics.
- Support across the data lifespan including research, monitoring, analysis, and evaluation.

Question #2: What technical assistance do tribes need to best support their data access and data quality needs?

Timely, Accurate, and Quality Data. Tribal leaders and Tribal organizations stated that a foundational issue is the need for access to timely, accurate and quality data. One commenter recommended that data include summary tables, graphs, and narratives. They noted that TECs can help provide this service with funding and support from HHS. Tribal leaders stated that HHS "should look toward a policy that provides tribal governments with appropriate capacity parity in access and use or require TECs to gain tribal consent and support for any public data reporting. Additionally, the policy should prioritize and require any TEC, agency, or contractor seeking to access, analyze, publish or release data that is geographically or tribally specific information receive tribal consent and approval prior to initiating their data efforts."

Timely Technical Assistance. Several commenters requested more expedient and responsive access to technical support. To facilitate this, respondents reiterated that HHS must root its policy in Tribal sovereignty with clear guidance outlining the PHA of Tribes and TECs. Lack of such uniform recognition across the HHS—and by states and local governments—hinders the provision of technical assistance, as well as access to data systems and analytics. One commenter recommended that IHS offer priority support for sites without IT shares or access. They also recommended IHS "ensure quality, up-to-date data storage and access systems."

Other Comments. Additional comments that HHS received in response to this question included, but are not limited to, the following:

- Request that CDC identify all datasets in its possession.
- Designate agency points of contact for public health data matters.
- 24/7 hotline for data-related technical assistance and remote data system access help.
- Data workforce capacity-building support.

Question #3: How have barriers to data access affected your efforts to address public health challenges?

Disadvantages Public Health Actions. Tribal leaders uniformly stressed the importance of timely, routine and immediate access to Protected Health Information (PHI) and other public health data in federal, state, and local data systems to address health disparities and emerging threats in Indian Country. Respondents shared that outdated and delayed data "puts tribes at a disadvantage" in addressing public health concerns. Several respondents also discussed how the lack of access to mental health and substance use data impacts Tribal policies, actions, and responses to mental and behavioral health crises.

Structural Challenges Contribute to Health Inequities. A few respondents described the current lack of data access and sharing by HHS as exhibiting "structural discrimination" that contributes to ongoing, well-documented health inequities in AI/AN populations. Several respondents shared that they currently receive data, which is itself limited, from the CDC (HHS PROTECT²) and IHS (Epidemiology Data Mart and limited other sources) but no other HHS agencies. Many commenters stated that available data often relies on manual manipulation for data retrieval and analysis, "which is time consuming and increases the likelihood of errors." This was particularly the case where the IHS electronic health record system and data were discussed.

Pandemic Impacts. Tribal leaders from diverse geographic locations described how limited or denied access to public health data was particularly impactful during the pandemic. One TEC commenter stated that the process for obtaining COVID-19 data from the CDC "was time-intensive and disorganized, and our attempts to understand the quality and limitations of the data were often met with non-response from the CDC." To address the situation, that respondent invested in a primary data collection system through a regional effort of the Tribes that strained their collective resources even as it benefited their pandemic response. Another TEC shared that it took over a year and half for it to gain access to HHS PROTECT COVID-19 data, which significantly impeded its work.

AI/AN-Specific Data Collection Insufficient, Inaccurate, or Absent. There were many recommendations that HHS review its data collection methods as they relate to AI/ANs. Tribal respondents raised the long-standing challenge of AI/AN identity misclassification and/or omission of racial/ethnic information during data collection. They further noted that where racial/ethnic information is collected, Tribal affiliation is almost never available. The lack of such information makes it difficult to identify Tribal data, as well as datasets and systems that may contain useful public health data for Tribes and TECs. Due to the potential sensitivity of this issue, at least two respondents suggested further consultation on this issue.

One respondent detailed specific ways in which HHS could develop best practices for data collection in AI/AN populations. These recommendations included expanding current metrics to account for structural factors that influence health, incorporating community input into data interpretation methods, and focused efforts on increasing data availability and quality on

² HHS PROTECT a secure data platform for the COVID-19 pandemic response accessible here: <https://public-data-hub-dhhs.hub.arcgis.com/>.

historically underserved groups (such as oversampling and using weighted sampling for AI/AN populations).

Question #4: What are some examples of the type of support that a TEC provides to your public health activities?

TECs Central to Public Health in Tribal Communities. Respondents consistently emphasized the invaluable role of TECs in advancing public health in Indian Country. Tribal leaders stressed that TEC PHA is derived from the delegation of a Tribal government's inherent PHA and must be respected accordingly. Many Tribal leaders stated that "[d]ata given to TECs is data given to tribes" because of the delegative authority on which TECs operate and serve Tribes.

Tribal Data Sovereignty Paramount. Respondents to this question often emphasized that while TEC assistance is invaluable, it must be preceded and cabined by Tribes remaining "in control of how their data is accessed, used, and released" through limited, express authorizations.

TECs Provide Services to Tribes in Myriad, Valuable Ways. Many of the commenters who responded to this question cited the seven core functions of TECs set forth under existing law to illustrate the types of support TECs provide to their Tribe(s).³ The seven core functions are:

1. Collect data relating to, and monitor progress made toward meeting, each of the health status objectives of the IHS, Tribes, Tribal organizations, and urban Indian organizations (UIOs) in the service area;
2. Evaluate existing delivery systems, data systems, and other systems that impact the improvement of Indian health;
3. Assist Tribes, Tribal organizations, and UIOs 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 healthcare delivery systems for AI/ANs;
6. Provide requested technical assistance to Tribes, Tribal organizations, and UIOs 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 Tribes, Tribal organizations, and urban Indian communities to promote public health.

Those who provided specific examples of how TECs support their Tribe's public health initiatives mentioned scenarios such as: weekly technical updates; providing material and medical supplies support; assisting Tribes in establishing electronic health record bridges to other data systems;

³ 25 U.S.C. § 1621m(b).

chronic and acute disease surveillance; capacity-building training; oral and written reports; among others. One TEC shared that it "responded to over 600 Tribal requests for data-related technical assistance" over the past five years.

Tribal leaders discouraged practices and policies that hinder TEC functions. For instance, one commenter noted, "TECs often find themselves in an untenable position where they need support for ongoing operations but cannot identify funding opportunities that are also supported by local tribal priorities or needs." They suggested that HHS focus on TEC functions and Tribal data sovereignty when offering agency support and funding opportunities.

Question #5: To what extent should HHS share tribal members' health information with TECs to facilitate their public health activities?

HHS received mixed comments pertaining to TEC access to Tribal member information. A few respondents stated that TECs should have access to all data, including personally identifiable information (PII), while many stated that TEC access must be limited and/or rest upon the informed consent of Tribe(s) due to Tribal sovereignty.

A few Tribes expressed concern about TEC access to Tribal data, including PHI of Tribal members, without the Tribe's consent. They pointed to language in the GAO report that found "officials from six of the nine TECs told us they had access to [IHS] patient registry data with certain patient identifiers removed—such as name, address, and social security numbers; while officials from the other three TECs told us they had access to data that included some of these identifiers."⁴ Those Tribes stated that the policy should have specific requirements for TECs to access Tribal data only upon informed Tribal consent, consistent with IHClA requirements.⁵

Question #6: What legal/policy barriers have you encountered at the state or local level for accessing data held by those jurisdictions?

Lack of Tribal and TEC PHA Status Recognition by Federal, State, and Local Jurisdictions. The primary response to this question by those who addressed it was that state and local jurisdictions simply do not recognize the PHA of Tribes and TECs and, therefore, do not share or allow access to data to the same level as other PHAs. Misinterpretation of HIPAA limitations as it pertains to Tribes and TECs was also frequently cited and a recommendation was made that "CMS clarify the HIPAA policy with respect to state and private entities data sharing with Tribes[.]" One respondent shared in illustration that, "TECs are often required to undergo lengthy negotiations and data sharing processes for data that are readily available to state health jurisdictions through much simpler processes. Requiring TECs to negotiate with multiple agencies introduces administrative complexity, additional costs and delays in data access. This is unacceptable."

⁴ GAO, Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access, GAO-22-104698 at 11-12 (March 2022).

⁵ 25 U.S.C. § 1621m(b).

Two respondents shared that it took a three-month negotiation for its TEC to enter into a data sharing agreement with the state during the pandemic. The negotiation process directly cut into the rapid response to outbreaks in rural communities. Ultimately, the data sharing agreement allowed for only a limited dataset to be temporarily shared with the TEC.

Data Sharing Inequities. Unequal data sharing practices were also cited as a barrier encountered at the state or local level. Tribal leaders noted that "some agencies will collect data, but fail to report Tribal or American Indian specific data publicly for use by Tribes and other agencies." They recommended HHS incentivize data sharing equity through agreements with federal, state, and local agencies.

Other Comments. Additional comments that HHS received in response to this question included, but are not limited to, the following:

- Some state reporting laws are not expressly inclusive of Tribal governments as PHAs.
- Improve data sharing between IHS and state health departments to ensure AI/AN data held by states is comprehensive.
- Inconsistencies in defining "Tribal lands" or using geographic or zip code markers to identify zones of reportable Tribal data that do not capture all Tribal data.

Question #7: If tribal affiliation is included in data collection, what are your recommendations for collecting and sharing that type of information?

Protect and Require Prior Informed Tribal Consent for Tribal Affiliation Data. Many Tribal respondents to this question recommended that control and release of any Tribal affiliation data should be restricted and require prior informed consent of the Tribe(s). One respondent stated that where Tribal affiliation data is already in a data system, it should only be shared with the Tribe to which it pertains. Almost all who addressed this question suggested that specific language in the Tribal Data Sharing Policy address how such information will be protected and managed.

Accurate AI/AN Population Data Needed. Tribal respondents emphasized the importance of accurate information specific to their populations for public health. Most stated that collecting Tribal affiliation data could be beneficial, as a general point. One respondent specified how "[a]ccurate and complete data on Tribal affiliation would allow Tribes and TECs to more accurately assess the health of specific Tribal communities, instead of relying on crude estimates based on race, ethnicity, geography of residence, and other proxy measures." Several commenters stated that regional Tribal data may also be beneficial to collect along with aggregate AI/AN population health data based on reservation residency (i.e., by zip code or "on or near" a reservation status).

Reporting of Tribal Affiliation Sensitive. At least one respondent noted that "self-reported data linked to tribal affiliation can lead to inaccurate representations of tribal communities." They urged Tribal affiliation data be governed, and verified, by Tribal governments "and only with support

and consent from Tribal governments or their designees." Use of aggregate data that includes Tribal affiliation without express Tribal consent and verification was discouraged. Another commenter recommended a contrasting position – use of Tribal affiliation rather than Tribal membership as, in their view, the "use of tribal affiliation allows for the collection of what an individual identifies with without impeding tribal sovereignty." The commenter also suggested that individual Tribal affiliation data be suppressed "if the reportable data contains less than 10 [individuals] of a specific tribal affiliation."

Negotiate Uniform Tribal Data Fields Across States. Another Tribal respondent stated that, "[u]nder the present system, there is no way of ascertaining which data is 'Tribal data' and which is not. To remedy this, a more specific data sharing scheme would have to be negotiated by the states, who feed the federal datasets. From a public health perspective, it would be ideal for all states to institute uniform fields in which citizens of federally recognized Tribal Nations are identified, as well as identifying the Nation of citizenship. Because of the potential for implications beyond public health, this is an item for further consultation between HHS and Tribal Nations."

Other Comments. Additional comments that HHS received in response to this question included, but are not limited to, the following:

- Where there is aggregate Tribal data of two or more Tribes, recommendation that it be released except where such release may be used to stigmatize Tribal populations.
- Establish regional TEC Tribal Data System Advisory Boards for partners to agree on policies, procedures, and data exchanges, including Tribal member data sharing.

Question #8: How can HHS agencies improve quality and utility of AI/AN health data?

HHS Employee Training. Several Tribal respondents recommended that HHS develop education and training around Tribal data sovereignty and data sharing for its employees. They pointed to findings in the GAO report indicating that many officials from the CDC and IHS were unaware of the federal law allowing Tribes and TECs to receive data for this recommendation.

Access to Substance Use Disorder (SUD) Data a Priority. Several comments touched upon access to SUD data, particularly that covered by the Part 2 regulations.⁶ Tribal leaders explained that such data is not available through the IHS Epidemiology Data Mart or through the Substance Abuse and Mental Health Services Administration. Respondents requested Tribal and TEC access to Part 2 and other SUD, mental and behavioral health data to better address these crises in Tribal communities. One respondent stated that it has had to rely on state data for certain information as a result, which is limited and incomplete in scope.

⁶ Part 2 regulations serve to protect the confidentiality of patient records created by federally assisted programs for the treatment of SUD. These restrictions are stipulated in section 543 of the Public Health Service Act, 42 U.S.C. 290dd-2, and further clarified in the Substance Abuse Confidentiality Regulations promulgated by the Substance Abuse and Mental Health Services Administration at 42 C.F.R. Part 2.

Address Shortcomings in Racial/Ethnic Classifications in Data Collection. Commenters discussed the quality of data available on AI/AN populations, which they found lacking. A key area for improvement is the correction of racial/ethnic classifications during the data collection process. Tribal leaders recommended removal of "Other" and "Multiracial" categories that contribute to misclassifications, as well as asking a specific question on Tribal citizenship prior to asking about Hispanic ethnicity to better capture AI/AN data (which could be part of the Office of Management and Budget's race/ethnicity data revaluation⁷). *See parallel discussion under Question #3.*

Other Comments. Additional comments that HHS received in response to this question included, but are not limited to, the following:

- Engage TECs to address state data misclassifications through data linkage and matches.
- Publish AI/AN data in all federally produced reports by presenting health data by race.
- Fully fund IHS Health Information Technology Modernization Initiative⁸; support Tribal communities in their data modernization efforts.
- Address interoperability issues across the HHS, Tribes, and TECs.

Other Specific Recommendations:

In addition to the common themes detailed above, HHS received many specific recommendations from Tribal leaders and Tribal organization leaders on factors that should be considered in association with the development of the new Tribal Data Sharing Policy. These included, but are not limited to, the following:

- Implementation of the policy no later than June 2023.
- Standardize protocols across IHS Areas and TECs; data sharing agreements be harmonized across HHS to allow uniform TEC and Tribal access to data and technical assistance.
- Require Tribal consent and support for Tribal data access provided to TECs, federal agencies, and partners that explicitly address intended use, publication, and any leveraging of other data, including through data warehouses.
- High data protection standards (such as on separate, firewalled servers with limited access).
- Consideration for historical trauma and experiences with misuse and abuse of Tribal data.

⁷ In June 2022, the Office of Management and Budget (OMB) launched a formal review to revise its Statistical Policy Directive No. 15, *Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity*. Directive No. 15 provides minimum standards that ensure our ability to compare information and data across Federal agencies, and also to understand how well Federal programs serve a diverse America. Further information on this review is available here: <https://www.whitehouse.gov/omb/briefing-room/2022/06/15/reviewing-and-revising-standards-for-maintaining-collecting-and-presenting-federal-data-on-race-and-ethnicity/>.

⁸ Additional information on the IHS Health Information Technology Initiative is here: <https://www.ihs.gov/hit/>.

- Develop single points of entry to access agency data (like a data hub) to ease administrative burdens and optimize accessibility for Tribes and TECs. Such data should be made available in "a structured format that can be automatically processed."
- Incorporate a provision into cooperative agreements between states and HHS agencies requiring a data sharing plan between states and TECs.
- Consider the recommendations in the OPEN Government Data Act; Improving DATA in Public Health Act; Indigenous Data Sovereignty Principles and Recommendations (Network for Public Health Law); and certain other third-party sources, like the Urban Indian Health Institute's *Best Practices for [AI/AN] Data Collection*.
- Establish a Public Health Information Sharing and Availability Advisory Committee within the CDC comprised of subject matter experts, national organization representatives, and others to advise on public health data matters.
- "Establish an interagency data council responsible for equity, racial justice, and social and public health data. The interagency council would prioritize systemic drivers of data inequities across HHS agencies, establish a process for sharing public health data, create a longitudinal and sustainable program, and receive updates on federal data violations."
- One request that the policy be developed through a negotiated rulemaking for a collaborative, consensus-based outcome.

CONCLUSION:

HHS extends its gratitude to the many Tribal leaders and Tribal organization leaders who have participated in this Tribal Data Sharing Policy consultation to date. HHS recognizes the critical importance of data access and exchange to public health in Tribal communities and throughout Indian Country. We are dedicated to addressing the GAO's recommendations as they relate to data sharing with TECs, and HHS will also address data sharing and Tribes. Data sharing is a part of the government-to-government relationship, which we are dedicated to honoring in our work and engagement with Tribal governments.

HHS NEXT STEPS:

HHS will take the recommendations, concerns, and comments garnered from Tribal leaders and Tribal organization leaders during the telephonic and written portions of this consultation to inform the development of our draft Tribal Data Sharing Policy that will provide guidance to all HHS Operating and Staff divisions on how to engage in data sharing with Tribes and TECs. This policy will also be flexible enough to allow for individual agencies to have their own Tribal data sharing policies in place that speak more specifically to their programs and policies. The HHS Tribal Data Sharing Policy will operate very similar to the HHS Tribal Consultation Policy in this respect.

We intend to prepare a draft of the HHS Tribal Data Sharing Policy by late winter 2023, at which point we will share back for further Tribal Consultation. We intend to have a final policy by late spring 2023.