NCVHS
National Committee on Vital and Health Statistics

December 12, 2022

The Honorable Xavier Becerra
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Re: Recommendations for HHS, States and Territorial Public Health Authorities to Improve Public Health Data Sharing with Tribal Epidemiology Centers (TECs) and Other Designated Tribal Public Health Authorities (ODTPHAs)

Dear Mr. Secretary:

The National Committee on Vital and Health Statistics (NCVHS) is charged with serving as your advisory body on health data, statistics, privacy, national health information policy, and the Department's strategy to best address those issues. In this role, the Committee reviews and comments on findings developed by other organizations and agencies including to make recommendations for their adoption or implementation.

The purpose of this letter is to provide specific recommendations for HHS action needed to improve the timely access to public health data for Tribal Epidemiology Centers (TECs) and other Designated Tribal Public Health Authorities (ODTPHAs) from federal, state, and local public health authorities and health care providers.[1] Our investigation shows longstanding barriers to data access by TECs and ODTPHAs that contributed to delays in responding to the COVID-19 public health emergency.

The Committee's recommendations are guided by the Foundations for Evidence-Based Policymaking Act of 2018[2] (Evidence Act). A major requirement of the Evidence Act is the development of Agency specific systematic plans for identifying and addressing priority questions relevant to improving federal programs, policies, and regulations. More generally, the Evidence Act also promotes improving access to data and expanding evaluation and other evidence-building capacity. The law established new legal expectations for openness and accessibility to enable leaders across government to work together to

[1] TECs, established by the Secretary of Health and Human Services, are granted authority under the Indian Health Care Improvement Act to carry out various public health functions related to the Indian Health Service Area they serve. TECs may also be designated by tribes to provide public health functions for their specific communities. In this regard, tribal governments may provide public health functions for their communities in a variety of ways and may use a combination of approaches. They may act directly through tribal health departments or designated personnel, participate in intertribal health boards, and/or authorize TECs or other organizations that serve American Indian and Alaska Natives to act on their behalf. *See* Indian Health Care Improvement Act, as amended, 25 USC § 1621m).

[2] Pub. L. 115-435, 132 Stat. 5529, *available at* https://www.congress.gov/115/plaws/publ435/PLAW-115publ435.pdf (visited Dec. 19, 2022).

coordinate data and evidence needs and uses. History demonstrates that Native American people are best served when tribal governments are empowered to lead their communities.[3] Our recommendations support and respect the data access policies that evolve from the sovereignty of tribal nations and that are implemented in consultation with tribal authorities.

Federal law requires the Secretary of HHS to establish a TEC in each Indian Health Service (IHS) area.[4] Currently, there are eleven TECs that serve geographic areas and one TEC to serve the needs of urban American Indians nationwide.[5] In consultation with and at the request of Indian tribes, tribal organizations, and urban Indian organizations, TECs provide support to protect public health and promote wellness of American Indian/Alaska Native (AI/AN) populations. TEC support to Indian tribes, tribal organizations, and urban Indian organizations may include disease surveillance and control, data collection and analysis, needs assessment and prioritization, and program development, implementation, and evaluation. TECs are deemed public health authorities for the purpose of the Health Insurance Portability and Accountability Act (HIPAA)[6] and shall have "access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information" in HHS' possession.[7] Additionally, as described below, state and local governments, health care providers, and others may provide data to TECs and ODTPHAs.

Tribal governments often rely on a TEC to implement public health functions on their behalf; the TEC may additionally, or alternatively, rely on an ODTPHA authorized to protect the public's health and promote wellness for its community. Under the HIPAA Privacy Rule,[8] a public health authority is defined as an agency or authority of the U.S., a state, a territory, a political subdivision of a state or territory, or an Indian 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.[9] A public health authority is responsible for public health matters as part of their official mandate, which include federal, state, territorial, TECs, and ODTPHAs. As public health authorities, HIPAA permits health care providers, health plans, and governmental agencies that are covered by HIPAA (''covered entities''), to disclose data, including identifiable data as reasonably necessary, to TECs and ODTPHAs so that they may perform their public health functions. HIPAA permits

[3] Memorandum from the President of the United States to Heads of Executive Departments and Agencies, "Tribal Consultation and Strengthening Nation-to-Nation Relationships," (Jan. 26, 2021) *available at* https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/26/memorandum-on-tribal-consultation-and-strengthening-nation-to-nation-relationships/ (visited Dec. 19, 2022).

[4] Congress established the Tribal Epidemiology Centers (TECs) in sec. 210 of the Indian Health Amendments of 1992, Pub. Law 102-573, 106 STAT. 4526, 4551 (Oct. 29, 1992)(amending the Indian Health Care Improvement Act), *codified at* 25 U.S.C. §1621m. *See "*Core Functions of Tribal Epidemiology Centers" on the website of the TECs available at https://tribalepicenters.org/7-core-functions/ (visited Dec. 22, 2022).

[5] There are 12 nationally recognized Tribal Epidemiology Centers. *See* CDC, Tribal Epidemiology Center Public Health Infrastructure Recipient Map (Feb. 8, 2019), https://www.cdc.gov/healthytribes/tecphi-map.htm (visited Dec. 22, 2022). A map and the symbols of each of the TECs may also be found on the TEC website at https://tribalepicenters.org/12-tecs/ (visited Dec. 22, 2022).

[6] Health Insurance Portability and Accountability Act, Pub. L. 104-191, 100 Stat. 2548.

[7] Tribal Epidemiology Centers, 25 U.S.C. §1621m.

[8] HIPAA Privacy Rule, 45 CFR 164 **Part 160 and Part 164 Subparts A and E.**

[9] HIPAA Privacy Rule, 45 CFR § 164.501.

a covered entity to rely on a TEC's or ODTPHA's reasonable representation of its legal authority and need for data to perform its intended public health purpose.[10]

During the NCVHS public meeting held on July 21, 2022, an expert panel briefed the Committee during the session, "Tribal Epidemiology Centers: Data Access and Privacy,"[11] which included a presentation on the March 2022 Government Accountability Office (GAO) report on this topic.[12] The Committee heard that the TECs, which are supported by the IHS, continue to experience significant difficulties accessing much-needed public health data held by federal, state, and local public health agencies as well as healthcare providers. This was confirmed by the HHS Office of the Inspector General (OIG), which conducted a similar study and developed a report just four months later. That report stated that the CDC should ensure that TECs have timely access to all public health data to which they are entitled.[13]

Not only do TECs have the legal authority to collect, receive, and disseminate public health data as necessary to respond to public health threats and needs, but ODTPHAs do as well. Panelists and participants of the public comment period articulated that federal, state, and local public health authorities are not aware of the legal authorities that permit TECs and ODTPHAs to access data. The Committee heard testimony requesting assistance for timely implementation of the recommendations in the GAO and OIG reports, including from Abigail Echo-Hawk, Director of the Urban Indian Health Institute (UIHI): "I urge you to make recommendations to the Secretary that take all of the recommendations that came out of the Government Accountability Office report. Every single one of those needs to be implemented. We need a timeline and the resources for that implementation to happen so that we can get access to the data that we need."[14]

NCVHS supports and endorses the GAO and OIG's recommendations which are listed in the Appendix to this letter. The GAO found that the presence of CDC and IHS data sharing systems, and agreements between the agencies and TECs, have facilitated TECs' access to a range of epidemiological data, including on COVID-19 cases and the health of IHS facility patients. However, several factors have also hindered TECs' ability to easily access needed HHS public health and health care data, including a lack of:

- documentation, policies, and procedures regarding the legal affirmation of TECs' authority and responsibilities to access HHS data;
- easily identifiable policies, clear procedures for TECs on how to request access to data, and HHS procedures for timely response;

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[10] See HIPAA Privacy Rule Minimum Necessary requirements, 45 CFR § 164.502(b); Verification requirements, 45 CFR § 164.514(d) and (j).

[11] *See* NCVHS Committee Meeting Agenda, July 20-21, 2022, *available at* https://ncvhs.hhs.gov/meetings/full-committee-meeting-11/ (visited Dec 22, 2022).

[12] GAO, Report No. 22-104698, "Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access," March 2022) *available at* https://www.gao.gov/assets/720/719375.pdf (visited Dec 22, 2022). A list of the five recommendations in the GAO report, all of which HHS agreed with, may be found in the Appendix.

[13] The two recommendations in the Office of Inspector General (OIG) report, with which CDC concurred, are listed in the Appendix. OIG, HHS, "CDC Found Ways to Use Data to Understand and Address COVID-19 Health Disparities, Despite Challenges with Existing Data." (July 2022), *available at* https://oig.hhs.gov/oei/reports/OEI-05-20-00540.asp (visited Dec. 22, 2022).

[14] Abigail Echo-Hawk, Director of the Urban Indian Health Institute (UIHI) and Executive Vice President of the Seattle Indian Health Board, *See* Transcript of July 21 2022, Expert Panel [Transcript] , at 41, *available at* https://ncvhs.hhs.gov/wp-content/uploads/2022/08/Transcript-Full-Committee-Meeting-7-21-2022-508.pdf (visited Dec. 22, 2022).

- guidance on the legal authorities for the provision of such data; and
- outreach to state and local public health and health care entities about their responsibilities.

Dr. Yvette Roubideaux (Rosebud Sioux), then Director of the National Congress of American Indians (NCAI) Policy Research Center, and former Director of the Indian Health Service made this statement during the public comment period:

> ….the Biden Administration with all of its work and executive orders on tribal consultation, executive orders on equity, data, and all of the initiatives that are related to this issue, it is time to fix this. . . . There is a lot of unconscious bias around the capabilities of the TECs and that has to stop. This administration cannot allow it. The situation is this is 2022. There are very qualified and talented epidemiologists in these tribal epidemiology centers. I trust them. I know that they are doing a great job. They are ready to serve their communities better through getting access to the data that they need. I would encourage HHS to actually use them as teachers for all the data people in HHS who are still to this day not utilizing data on American Indians and Alaska Natives in the most effective manner.[15]

The GAO and OIG reports focus their recommendations primarily on the barriers to data access from HHS agencies. However, the expert panel provided testimony that TECs also encounter significant obstacles to access data from state and local health departments.[16] The Network of Public Health Law has also identified difficulties in accessing authorized data from healthcare providers.[17] A recent "report card" on CDC and state COVID-19 surveillance data for American Indian/Alaska Native (AI/AN) populations reveals a wide and unsettling variation among the states in their provision of such data.[18] Fourteen states did not include AI/AN populations in their state dashboards in the period January 2020 – January 2021; 23 states reported less than 70% of their COVID cases with complete racial information.

As is the case with state and local health departments, TECs/ODTPHAs need timely access to public health data for managing public health emergencies (PHEs) as well as carrying out essential public health functions. Without access to timely data, TECs/ODTPHAs do not have sufficient information upon which to base decisions and actions affecting millions of AI/AN people.

The Committee heard other examples of inability to access data necessary to serve their communities and the experience of receiving data of such poor quality that the TEC was unable to use it. Jerilyn Church, Chief Executive Officer, Great Plains Tribal Leader's Health Board said:

> [O]ur medical epidemiologists received a message . . . . [expressing] frustration from one of our tribal elected leaders who has been working for over a year to get specific COVID-

[15] Transcript, at 53-54.
[16] *See* Statement of Kristin Eklund, Transcript, at 36; Statement of Tricia Roy, at 38; Statement of Jerilyn Church, at 46; Statement of Abigail Echo Hawk, at52.
[17] Sallie Milam, "Improving Data Sharing for Tribal Health: What Public Health Departments Need to Understand About HIPAA Data Privacy Requirements," (Network for Public Health Law, Dec. 2, 2021), *available at* https://www.networkforphl.org/news-insights/improving-data-sharing-for-tribal-health-what-public-health-departments-need-to-understand-about-hipaa-data-privacy-requirements/ (visited Dec. 22, 2022).
[18] Vickie M. Mays, Abigail Echo-Hawk, Susan D. Cochran, and Randall Akee. "Data Equity in American Indian/Alaska Native Populations: Respecting Sovereign Nations' Right to Meaningful and Usable COVID-19 Data," 112 Am. J. Pub. Health 10, *available at* https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2022.307043 (visited Dec. 22, 2022).

> 19 vaccination information for their community from IHS. They know the percentage that was vaccinated but they do not know how to break that down by age, by gender, location. They do not know who has been vaccinated and who has not. They do not know who they need to reach out to, which communities to encourage vaccination or provide the education that they may need on the benefits of vaccination.[19]

Abigail Echo-Hawk, Director of the Urban Indian Health Institute (UIHI), stated:

> During the COVID-19 pandemic, we fought for data, worked with members of Congress. It took two congressional hearings, a letter from 26 members of Congress for tribal epidemiology centers to finally get data. We get that data. My team and I realize the data is of such poor quality that the report we were able to publish on that was actually one I title data genocide and the fact that the elimination of American Indians and Alaska Natives in these data sets directly resulted in my relatives' deaths, the deaths in my communities individually, the communities that Jerilyn works within, and the communities across this country.[20]

Based on the information provided to the Committee by the expert panel, NCVHS concurs with and supports the GAO and OIG recommendations, however, those recommendations focus *only* on access by TECs to HHS public health data. Therefore, NCVHS makes the following additional recommendations to HHS:

1. Expand the December 2020 guidance regarding public health authorities under HIPAA[21] to clarify that all American Indian/Alaska Native (AI/AN) entities designated as public health authorities — including Tribal Epidemiology Centers (TECs) and Other Designated Tribal Public Health Authorities (ODTPHAs) — meet the definition of "public health authority" in 45 CFR §164.501 and should be able to access data on the same basis as any other public health entity so that they can carry out their mission to protect the public's health.

   This guidance would clarify that covered entities may disclose protected health information (PHI)[22] for public health purposes without patient authorization to TECs/ODTPHAs as public health authorities under 45 CFR 164.512(b). The guidance should clarify that covered entities may rely upon TEC/ODTPHA minimum necessary[23] determinations with respect to requested public health data, as they would with any other public health authority.

2. Given the importance of the Government Accountability Office (GAO) and Office of Inspector General (OIG) recommendations, prioritize their rapid implementation, determine any gaps in their implementation, and develop a plan to close those gaps to complete implementation quickly.

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[19] Transcript, at 44.
[20] *Id.*, at 42.
[21] OCR, "HIPAA, Health Information Exchanges, and Disclosures of Protected Health Information for Public Health Purposes" (Dec. 18, 2020) *available at* https://www.hhs.gov/sites/default/files/hie-faqs.pdf (visited Dec. 22, 2022).
[22] 45 CFR § 160.103.
[23] The HIPAA Privacy Rule requires most disclosures to follow the "Minimum Necessary" standard requiring a covered entity to "implement policies and procedures (which may be standard protocols) that limit the protected health information disclosed to the amount reasonably necessary to achieve the purpose of the disclosure." 45 CFR § 164.514(d)(3)(i). A covered entity is entitled to "rely, if such reliance is reasonable under the circumstances, on a requested disclosure as the minimum necessary for the stated purpose when (A) Making disclosures to public officials that are permitted under § 164.512 [including public health authorities], if the public official represents that the information requested is the minimum necessary for the stated purpose. *See* 45 CFR § 164.514(d)(d)(iii).

3. Lead a collaborative national effort to provide Tribal Epidemiology Centers (TECs) and Other Designated Tribal Public Health Authorities (ODTPHAs) timely access to all requested public health data recognizing that their data needs are not limited to data provided by HHS Operating Divisions (Centers for Disease Control and Prevention, Indian Health Service, Centers for Medicare and Medicaid Services, etc.). TECs and ODTPHAs have an urgent need for public health data from states, local agencies, and health care providers to support and conduct public health in their areas of responsibility. In its federal leadership capacity, the Department of Health and Human Services (HHS) should identify constructive approaches (e.g., distribute clear written guidance, public outreach, etc.) to instruct all federal, state, and local public health entities that TECs/ODTPHAs are designated as public health authorities in order to facilitate their unobstructed, timely access to authorized public health data.
4. Investigate and determine the infrastructure, communication, and personnel needs necessary to improve Tribal Epidemiology Centers' (TECs') and Other Designated Tribal Public Health Authorities' (ODTPHAs') data exchange systems, data modernization needs, and other data infrastructure capacity for a timely and quality response in meeting the public health data and surveillance requirements for American Indian/Alaska Native (AI/AN) populations. This could include, for example, disseminating explanatory information to state and local public health agencies; facilitating the development of common templates for data sharing agreements; and providing consultation or technical assistance for specific data sharing issues.
5. Identify and publicize a process within the Department of Health and Human Services (HHS) through which Tribal Epidemiology Centers (TECs) and Other Designated Public Health Authorities (ODTPHAs) can seek redress should barriers arise for the timely access of such data.

Additional Considerations

While not recommendations, the following additional information outlines areas for consideration by HHS as the Department evaluates its approach to promoting best practices as the standard for sharing high quality data with AI/AN tribal and urban populations for health care and public health surveillance.

The Urban Indian Health Institute (UIHI), one of the 12 TECs, recommends best practices for public health and health care data collection about AI/AN populations.[24] These recommended best practices are grounded in sovereignty approaches of indigenous values and practices. The UIHI report recommends a model of indigenous health equity that asserts that collaboration with Native communities and tribal leadership is needed to collect meaningful data. As HHS considers ways in which to revise its data collection and classification procedures to achieve equity, it should consider the recommendations described in this TEC's advisory.

In addition, as part of achieving better quality and equity in standing of AI/AN health entities, HHS may consider the recommendation of the National Indian Health Board for tribal health departments to seek accreditation in accordance with standards of the Public Health Accreditation Board for tribal health

[24]Urban Indian Health Institute, "Best Practices for American Indian and Alaska Native Data Collection," (Aug. 25, 2020), *available at* https://www.uihi.org/resources/best-practices-for-american-indian-and-alaska-native-data-collection/ (visited Dec. 22, 2022).

departments.[25] While adhering to agreements of sovereignty, consideration of how accreditation for the tribal health departments can be worked out needs further exploration.

NCVHS focuses on the TECs/ODTPHAs' data access challenges through the recommendations in this letter. However, the Committee noted that the TECs/ODTPHAs also need meaningful, timely, actionable public health data. Currently, significant problems exist in AI/AN health data collected outside of AI/AN governments, including problems related to collection coverage and methods, data quality (e.g., completeness, accuracy, AI/AN definition, tribal affiliation), data analysis, storage, use (e.g., standardization of terminology, rules on the use of multi-racial classification within small populations), privacy and security requirements for data release, and data aggregation or disaggregation standards. NCVHS is available to assist HHS to determine best strategies, practices, and procedures to improve the data to support the health of urban and tribal AI/AN members.

The input from the expert panel presentations and discussion in combination with the input provided during the public comment period provide compelling support for HHS to act now.

Thank you for considering the recommendations outlined in this letter. The Committee stands ready to assist the Department on these issues. We are available to answer any questions and will continue to support HHS efforts to ensure that TECs and ODTPHAs have the same access to data as all public health authorities in the United States.

Sincerely,

Jacki Monson, J.D., Chair
National Committee on Vital and Health Statistics

Enclosure

Cc: Benjamin Sommers, ASPE
Roselyn Tso, IHS
Rochelle Walensky, CDC

[25] Nat'l Indian Health Bd., "Accreditation for tribal public health departments," (undated) *available at* https://www.nihb.org/public_health/accreditation_101.php (visited Dec 22, 2022).

APPENDIX

Recommendations of the Government Accountability Office (GAO)

The recommendations of the March 22 GAO report, "Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access," were as follows:

Recommendation 1: 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.

Recommendation 2: 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.

Recommendation 3: 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.

Recommendation 4: 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.

Recommendation 5: 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.

The Department agreed with each of these recommendations.

Recommendations of HHS Office of Inspector General (OIG)

The July 22 HHS Office of Inspector General report, "CDC Found Ways to Use Data to Understand and Address COVID-19 Health Disparities, Despite Challenges with Existing Data" recommended that CDC:

Recommendation 1: expand efforts both to improve racial and ethnic data associated with COVID-19 and to supplement them with additional data sources

Recommendation 2: ensure that TECs have timely access to all public health data to which they are entitled. CDC concurred with both recommendations.

CDC concurred with each of these recommendations.