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Facilitating the Urgent Public Health Need to Improve Data Sharing With Tribal Epidemiology Centers

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Abstract

Tribal Epidemiology Centers (TECs) are an essential and unique part of the public health system and an important part of federal efforts to improve the health status of American Indian and Alaska Native people. Pursuant to federal statute, TECs serve the 574 federally recognized Tribes (hereinafter, "Tribes") and their members across the United States, as well as American Indian and Alaska Native people in general. The COVID-19 pandemic has highlighted the need for timely, complete, and accurate public health data, particularly for American Indian and Alaska Native communities and others who may have been disproportionately impacted by COVID-19. This article reviews the history and importance of TECs and federal statutes governing TECs' ability to access and use protected health information for public health purposes. TECs and Tribes often encounter difficulty receiving public health data from state and federal agencies despite their designation as "public health authorities" under the Health Insurance Portability and Accountability Act and associated regulations. Limited access to this information hinders the statutory mission of TECs as well as Tribal monitoring of and response to public health threats such as SARS-CoV-2. Agency acknowledgment and compliance with current federal law regarding data sharing with TECs are essential to improve data access and the fragile public health of Tribal communities.

Keywords

American Indian/Alaska Native, public health law, public health data sharing and access, HIPAA, Indian Health Care Improvement Act, Tribal Epidemiology Centers

Tribal Epidemiology Centers (TECs) were first approved by Congress in 1992 as part of amendments to the Indian Health Care Improvement Act (IHCIA).[1] The first TECs were established in 1996 in the Phoenix, Portland, Great Lakes, and Alaska Indian Health Service (IHS) Areas.[2] From 1996 to 2006, a total of 11 TECs were established to serve the American Indian and Alaska Native (AI/AN) Tribes and Tribal organizations in each of the 12 IHS Areas, and 1 TEC was established to serve urban Indian organizations nationally.[2] TECs have 7 core functions mandated by federal law, performed "[i]n consultation with and on the request of Indian Tribes, Tribal organizations, and urban Indian organizations."[3] The functions are the following: "(1) collect data relating to, and monitor progress made toward meeting, each of the health status objectives of the [Indian Health] Service, the Indian Tribes, Tribal organizations, and urban Indian organizations in the Service area; (2) evaluate existing delivery systems, data systems, and other systems that impact the improvement of Indian health; (3) assist Indian Tribes, Tribal organizations, and urban Indian organizations in identifying highest-priority health status objectives and the services neeeded 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 health care delivery systems for Indians and urban Indians; (6) provide requested technical assistance to Indian Tribes, Tribal organizations, and urban Indian organizations 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 Indian Tribes, Tribal organizations, and urban Indian communities to promote public health."[3]

In 2010, the IHCIA was permanently reauthorized as part of the Patient Protection and Affordable Care Act, providing TECs with stable, continuous funding.[3] It affirmed and enhanced the trust responsibility of the federal government to deliver improved health care to millions of AI/AN

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people.[4] Congress recognized that TECs are an essential part of the federal policy goal of improving AI/AN health care.

To our knowledge, the legal foundation that permits disclosure of protected health information to TECs has not been considered in the public health peer-reviewed literature. Attorney and law professor Aila Hoss has written articles[5,6] on the subject for legal journals, and the Council of State and Territorial Epidemiologists published a report on legal issues concerning sharing identifiable health data between state and local public health authorities and TECs[7] in 2009, prior to the permanent reauthorization of the IHCIA, with a revision in 2011. We attempt to address this deficit here.

TECs Are Public Health Authorities

Indian Self-determination, Trust Responsibility

Although it is the IHS's obligation to expend appropriated funds to operate the 12 TECs, the TECs are Tribally operated institutions. The rights of Tribes to operate the TECs were created in the legislation and follow the federal policy of Tribal self-determination that began with the passage of the Indian Self-Determination and Education Assistance Act of 1975.[8] This policy continues through the IHCIA and its amendments.

The congressional findings of the 2010 IHCIA amendments note the federal responsibility to provide health services to AI/AN people to "eradicate the health disparities between Indians and the general population of the United States."[9] In the 2010 legislation, Congress also made an important policy statement within the law, saying "in fulfillment of its special trust responsibilities and legal obligations to Indians" that "it is the policy of this Nation . . . to ensure the highest possible health status for Indians and urban Indians and to provide all resources necessary to effect that policy."[10] In support of this policy, Congress made the amendments to federal law funding the TECs and vesting them with epidemiologic and public health functions.[4]

Congress also said that it would allow Tribes and Tribal organizations to operate the programs and services provided under the IHCIA "to ensure maximum Indian participation in the direction of health care services, so as to render the persons administering such services and the services themselves more responsive to the needs and desires of Indian communities."[10] Although operated by Tribes or Tribal organizations, the TECs are quasi-federal in their status, and this is how they are to be regarded in carrying out these public health functions. The 2010 amendments clearly indicate that Congress intends to continue to remain active in the field of Indian health improvement.

IHCIA and HIPAA

As referenced previously, the 2010 IHCIA included new language on the legal status of TECs, whether operated by Tribes, Tribal organizations, or the federal government. First, TECs were designated as public health authorities under the Health Insurance Portability and Accountability Act (HIPAA), which allows them to access protected health information.[3] HIPAA provides for the privacy and security of protected health information.[11] Covered entities, such as health care providers, health plans, and health care clearinghouses, generally may disclose an individual's protected health information only with his or her written authorization.[12,13] HIPAA's Privacy Rule, however, identifies "uses and disclosures for which an authorization or opportunity to agree or object is not required," including disclosures for "public health activities."[14] Public health authorities may receive protected health information under the Privacy Rule "for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions."[14] Regarding the Privacy Rule, the IHCIA states that all TEC activities "shall be for the purposes of research and for preventing and controlling disease, injury, or disability" as required in HIPAA.[3]

25 USC §1621m

In addition to providing the legal designation necessary for TECs to receive protected health information under HIPAA, the 2010 IHCIA mandated data sharing by the secretary of the US Department of Health and Human Services (HHS) with TECs.[3] HHS houses 11 divisions and holds a variety of protected health information on AI/AN people, which could be used to inform public health activities.[15] The 2010 IHCIA instructed that these data, including protected health information, be shared with TECs to address the public health needs of Tribal communities, stating "[t]he Secretary shall grant to each epidemiology center described in paragraph (1) access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary."[3] Some examples of protected health information that could be disclosed to TECs for public health purposes include health records from the 2.5 million AI/AN people who receive health care from IHS, claims data from the >150 million Americans who use programs housed within the Centers for Medicare & Medicaid Services, and the multiple national public health databases maintained by the Centers for Disease Control and Prevention.[16-18]

These 2 provisions of the IHCIA—TECs are public health authorities and the congressional mandate for the disclosure of protected health information to TECs by HHS—provide a strong legal foundation for the disclosure of protected health information to TECs. However, few opportunities exist for standardized protected health information disclosure to TECs from HHS agencies. This protected health information, which could be lifesaving, is seldom disclosed to TECs.

HHS Policy on Disclosure of Public Health Information to TECs

The IHCIA established TECs and the federally mandated framework to provide TECs access to public health data needed to perform their functions. However, HHS and many of its agencies and offices lack consistent, clear policy guidance that would make data accessible.

IHS has a unique relationship with TECs. IHS provides direct health care services for 2.56 million AI/AN people belonging to 574 federally recognized Tribes across the country through a variety of federal, Tribal, and urban programs.[16] Through their direct health care services, IHS clinical facilities collect health data on the AI/AN population. TECs were created to support each IHS service area and serve the AI/AN population.[3] Two data-sharing agreements are currently available between TECs and IHS to exchange health information. The first is a data-sharing contract for analyzing health data.[19] This agreement provides TECs access to information housed within IHS's Epidemiology Data Mart. Data are provided at IHS's discretion a few times per year and contain a limited deidentified dataset.[20] A second pilot project, established in 2019 with 1 TEC, provides a list of people with certain identifiers who have received services through IHS, Tribal facilities, or urban Indian programs.[20] These lists help correctly identify AI/AN people in state or federal databases, thereby improving the quality of data.[20]

While these agreements provide the possibility of limited data sharing between TECs and IHS, no agency-wide policy mandates the distribution of protected health information to TECs for public health activities in accordance with federal statute.[3,21]

Recent Developments

On January 21, 2021, President Biden signed executive order 13994, Ensuring a Data-Driven Response to COVID-19 and Future High-Consequence Public Health Threats.[22] This order states that "the heads of all executive departments and agencies (agencies) shall facilitate the gathering, sharing, and publication of COVID-19–related data . . . to the extent permitted by law." Key administration leaders, including the secretary of HHS, were directed to "promptly designate a senior official to serve as their agency's lead to work on COVID-19– and pandemic-related data issues" and move to "make data relevant to high-consequence public health threats, such as the COVID-19 pandemic, publicly available and accessible."[22]

This executive order was followed by a March 2022 report by the US Government Accountability Office, which found that "[a] lack of policies affirming TECs' authority to access HHS data" and "[a] lack of guidance for TECs on how to request data, and agency procedures on how to respond to such requests" hindered the ability of TECs to perform their mandated functions.[21] The US Government Accountability Office made 5 recommendations to improve TEC access to HHS data, including creation of HHS "policy clarifying the HHS data . . . that are to be made available to TECs as required by federal law."[21]

Implications for Public Health Policy and Practice

As set forth by President Biden in an executive order,[23] health equity is a policy goal of the executive branch and a general policy goal of the United States regarding AI/AN people and Tribes. TECs originated 30 years ago to help address health inequities experienced by AI/AN communities, and Congress provided the mandate and legal framework for them to do so. Federal agencies, however, have been slow to fulfill that mandate, with a disparate impact on the health of AI/AN people.

While there has been a general policy push to protect individual patient information, that must be balanced against the needs of Tribal public health organizations to protect AI/AN communities from public health threats, such as COVID-19. Fortunately, current federal law allows for regulated disclosure of protected health information to TECs under the same statutes governing data sharing for local and state health departments. Covered entities, other public health authorities, and federal agencies can disclose protected health information to TECs just as they do to other public health authorities. The lack of disclosure, when it occurs, hinders the ability of TECs and Tribal governments to monitor for and respond to public health threats. Disclosure of protected health information to TECs can be done in accordance with federal law, protecting the privacy of the individual and the health of the community, and can help achieve equity in data sharing that federal law and executive orders mandate.

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