

Barriers and Opportunities for Tribal Access to Public Health Data to Advance Health Equity

Carrie Field, Sarah Price, and A.C. Locklear

Keywords: Tribal Sovereignty, Public Health Authority, American Indian and Alaskan Native Health, Data Sharing, Electronic Case Reporting

Abstract: Public health authorities (PHAs), including Tribal nations, have the right and responsibility to protect and promote the health of their citizens. Although Tribal nations have the same need and legal authority to access public health data as any other PHA, significant legal challenges continue to impede Tribal data access.

Introduction

In 1926, Secretary of the Interior Hubert Work requested a comprehensive assessment of “the economic and social condition of the American Indians.”¹ The resulting 1928 Meriam Report demonstrated staggering health inequities across Tribal communities and recommended “establishing an adequate system of medical reports, records, and statistics...to use as a basis for analyzing problems, measuring results, and determining policies.”² Today, data is recognized as foundational to public health. Yet nearly 100 years after this urgent recommendation, Tribal public health authorities still lack reliable access to public health data.

Carrie Field, M.P.H. is a Senior Policy Analyst at the National Indian Health Board (NIHB) in Washington, D.C. **Sarah Price, M.P.H.** is a Programs Director with the National Indian Health Board in Washington, D.C. **A.C. Locklear, J.D.** is the Federal Relations Director for the National Indian Health Board in Washington, D.C. Mr. Locklear is a citizen of the Lumbee Tribe of North Carolina.

The consequences of stymied data access are severe and long-lasting. During the COVID-19 pandemic, real-time data was crucial for effective Tribal emergency response. However, vital data was delayed up to seven months before reaching Tribal Epidemiology Centers (TECs).³ In 2023, “data access issues” were cited as a complicating factor undermining Tribal response to an alarming rise in congenital syphilis rates in Tribal communities in the Great Plains,⁴ contributing to a local American Indian and Alaska Native (AI/AN) infant mortality rate that is likely now 2.5 times the overall rate for South Dakota.⁵ These are merely two examples of the inequities in health outcomes resulting from inequitable systems and laws.

Such inequities compound over time and diminish life expectancy. Life expectancy for the AI/AN population is now only 65.2 years: 11 years less than the overall American population.⁶ This devastating inequity is the culmination of thousands of legal and ethical choices made in the United States about how to govern and where to allocate resources — including choices made about public health law, systems, and infrastructure. Systemic exclusion of Tribes in the development of national public health infrastructure continues to drive serious health inequities experienced by AI/AN people.

Background

As sovereign nations, Tribes have always protected the wellbeing of their citizens by practicing public health according to each Tribes’ governance structure, Indigenous ways of knowing, and cultural values. Traditional Tribal public health systems were weakened by the arrival of European colonizers on the continent. “As the foreign powers’ presence expanded and with

the establishment and growth of the United States, Tribal populations dropped dramatically, and Tribal sovereignty gradually eroded.⁷ As in many areas of governance, public health for Tribes was made dependent on the federal government.

Subsequently, Tribal public health systems developed differently from state and local counterparts. While states and localities formed health departments as distinct public health entities, Tribal public health services were often integrated with healthcare and historically provided through the Bureau of Indian Affairs and later the Indian Health Service (IHS). However, this paternalistic federal approach proved ineffective. Government reports⁸ throughout the past century have repeatedly found that IHS “health facilities are frequently inaccessible and medically obsolete, and preventive care and specialty services are not readily available,” concluding that without substantial change, “health conditions are not likely to improve and will likely worsen.”⁹

Following a shift towards increased Tribal self-governance of health programs, public health services are now provided through an uneven patchwork of programs provided by Tribal governments, IHS, Centers for Disease Control and Prevention (CDC), TECs, and state and local health departments.

AI/ANs are simultaneously citizens of three sovereigns: the United States, their state of residence, and the Tribe in which they are enrolled. However, public health infrastructure in the United States has developed with states at the center, with strong deference to state public health authority. For public health surveillance, disease reporting is typically governed by state law and managed by state data systems. After data deidentification, certain data is also shared with CDC. In this system driven by federalism, Tribes have no clear place.

Tribal Sovereignty and Inherent Public Health Authority

Tribal nations’ inherent sovereignty is the legal basis for the status of Tribes as public health authorities. Public health authority refers to the legal authority of a sovereign government to engage in public health activities as part of its official duties, to protect and promote the health of the people within its jurisdiction.

Tribal sovereignty — the inherent right or power of Tribes to govern themselves — has been repeatedly affirmed by the U.S. Supreme Court, the U.S. Constitution, and hundreds of Indian treaties and federal statutes. Tribal sovereignty is a critical principle of Federal Indian law — the body of law that defines

the rights, relationships, and responsibilities between Tribes, states, and the federal government. Federal Indian law recognizes that (1) Tribes retain all of their inherent sovereignty that the federal government has not encroached upon through plenary powers; (2) the federal government, and not states, mediate Indian affairs; and (3) the U.S. has assumed a trust responsibility towards Tribal nations to provide for the health of AI/AN people, resulting from treaties and the role the U.S. assumed by limiting Tribal sovereignty.¹⁰

Like all sovereigns, Tribes maintain authority to execute public health functions to protect the health of their citizens. While the federal government has concurrent authority, no laws exist that divest Tribes of this authority.¹¹

Recognition of Tribal Public Health Authority in Federal Law

No federal law is needed to grant Tribes the authority to engage in public health activities; this authority is inherent to sovereign governments. However, federal law has recognized Tribal public health authority and, in the case of TECs, granted public health authority for data access.

Federal law acknowledges Tribal public health authority. For example, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) defines “public health authorities” to include state, local, and Tribal agencies and grants access to identifiable health information otherwise protected under federal law to prevent or control disease or injury.

While Tribes have the authority to conduct public health activities, many Tribes do not have the resources or infrastructure necessary to establish a public health agency. In recognition of this failure of the U.S. public health system to include Tribes, Congress established TECs in the Indian Health Care Improvement Act (IHCIA) to conduct supplemental public health activities on behalf of — and in consultation with — the Tribes.¹² The Patient Protection and Affordable Care Act permanently reauthorized IHCIA and designated TECs as public health authorities for the purposes of HIPAA.¹³ IHCIA also states that the Secretary of Health and Human Services “shall grant to each epidemiology center ... access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary.”¹⁴ As Tribes are also public health authorities, they also have the right to access health data in the possession of the Secretary.

Tribal public health authorities — including both Tribes and TECs — have the right, responsibility, and legal authority to access public health data.

Challenges to Data Access

Despite clear public health authority, Tribes and TECs continue to face immense barriers to accessing data.

Because states govern most public health data systems, states become the de facto arbiters of access to public health data. Tribes often find themselves at the mercy of individual relationships between the Tribe and state government officials. Considering the often fraught history between states and Tribes, this is not a recipe for data equity.

Even in states with positive relationships with Tribes, challenges persist. Some states have passed data privacy laws that restrict state data sharing, without clearly including an exemption for state agencies

to establish necessary and beneficial data sharing agreements.²⁰

Federal inaction persists despite urgent needs and in violation of federal law. As Tribes develop their public health systems, without timely access to public health data, Tribes cannot adequately track the spread of disease, make data-informed decisions, identify those at high risk for severe illness or mortality, or evaluate public health interventions.

Opportunities for Success: Electronic Case Reporting

Electronic Case Reporting (eCR) is the “automated, real-time exchange of disease case reports between

Because states govern most public health data systems, states become the de facto arbiters of access to public health data. Tribes often find themselves at the mercy of individual relationships between the Tribe and state government officials. Considering the often fraught history between states and Tribes, this is not a recipe for data equity.

to share essential Tribal data with Tribes. Challenges also frequently result from state officials’ lack of understanding around Tribal sovereignty and Tribal public health authority, including among states’ legal counsel.¹⁵ These are continued iterations of the observation made in the 2018 Broken Promises report: “Unequal treatment of tribal governments and lack of full recognition of the sovereign status of tribal governments by state and federal governments, laws, and policies diminish tribal self-determination and negatively impact ... health ... outcomes for Native Americans.”¹⁶

In some cases, federal agencies hold the data Tribal public health authorities need. However, a 2022 Government Accountability Office (GAO) report found that federal agencies have failed to comply with federal law by withholding health data from TECs.¹⁷ Little progress has resulted since.¹⁸ Two of the GAO report’s recommendations concerned IHS, which holds critical health data needed by Tribal public health authorities. As of the most recent update from the GAO, these recommendations remain unfulfilled.¹⁹ With no mechanism to enforce the law, Tribes are left with little recourse.

These access issues are compounded by the federal underinvestment in Tribal public health infrastructure, resulting in outdated health data systems and insufficient access to Tribal epidemiologists, data scientists, informaticists, and the legal counsel needed

electronic health records (EHRs) and public health authorities.”²¹ Public health authorities use data on reportable conditions to prevent and control outbreaks, monitor disease, and protect their communities’ health. Effective surveillance relies on the quick transfer of patient and clinical information. eCR provides an immediate transfer of case reports and strengthens the interoperability between healthcare and public health. This means faster response time, more timely and complete data, and better communication across the health sectors. During outbreaks, this can significantly reduce disease morbidity and mortality.

Providers and laboratories must report on certain conditions based on laws and policies within their jurisdiction. Historically, reporting required that providers and laboratories actively send information to the public health authority, which relied on provider knowledge of disease reporting laws. eCR eliminates this barrier. When a patient is diagnosed with a reportable condition, the EHR data automatically triggers a case report that is sent to all appropriate public health authorities.

eCR sends data to *all* appropriate authorities automatically and simultaneously, allowing Tribes to equitably receive data within their jurisdiction. This allows for clear recognition of Tribes as public health authorities and ensures that Tribes receive public health data regardless of data sharing relationships with the state.

Although eCR does not eliminate all challenges, and data sharing agreements with state and local governments are still necessary to ensure complete data, eCR has the potential to significantly improve health equity through honoring Tribal data sovereignty.

Paths Forward

As CDC, IHS, and other federal agencies pursue data modernization, Tribes must be fully included in planning and policymaking to ensure the next generation of health data systems does not continue to obstruct effective Tribal public health services. In addition, more work is needed to improve state data sharing with Tribes, beginning with more Tribal consultation and training on Tribal sovereignty and public health authority. Enforcement mechanisms are also needed to compel federal agencies to comply with federal law and share all necessary data with Tribes and TECs.

Finally, Congress must appropriate sufficient funding for AI/AN health to address the chronic shortfalls of the previous decades that have led to the current entrenched health disparities. As the 2018 Broken Promises report noted, “At least in policy, the nation has clearly stated its promise to Native Americans. But laws and policies are meaningless without resources to enforce them.”²² The current 11-year disparity in life expectancy is a stunning indictment of the United States’ failure to fulfill its trust and treaty obligations to American Indians and Alaska Natives. This is both a legal and an ethical failing.²³

Health equity has been defined as the “assurance of the conditions for optimal health for all people by valuing all populations equally, recognizing and rectifying historical injustices, and providing resources according to need.”²⁴ The United States must rectify the historical injustices of coercion, paternalism, and underinvestment by expanding Tribal self-governance, investing in building Tribal public health capacity, including Tribes in policymaking, and respecting Tribal sovereignty.

To address the health inequities resulting from colonization and federal paternalism, Tribal sovereignty must take center stage in the path forward, starting with developing public health data systems that grant Tribes equitable access to data.

Acknowledgements

The National Indian Health Board’s project to support electronic case reporting for Tribes is supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS), with 100 percent funded by CDC/HHS. The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement by, CDC/HHS or the U.S. Government.

References

1. L. Meriam, The Institute for Government Research, *The Problem of Indian Administration*, The Meriam Report to Honorable Hubert Work, Secretary of the Interior (February 21, 1928).
2. *Id.*
3. U.S. Government Accountability Office, *Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access*, Report to Congressional Addressees, GAO-22-104698 (March 2022), available at <<https://www.gao.gov/assets/gao-22-104698.pdf>> (last visited November 20, 2023).
4. National Center for HIV, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention, Department of Health and Human Services, *Undetermined Risk Factors for Syphilis Transmission among American Indians – Great Plains Area, 2022-2023* (July 21, 2023), available at <<https://www.greatplaintribalhealth.org/downloads/health-topics/tribal-epidemiology-center/sexual-health-education/180-gptlhb-epi-aid-syphilis-transmission-risk-factors-out-briefing-presentation-8-1-23/file.html>> (last visited November 20, 2023).
5. Author calculations based on data from unpublished Great Plains Tribal Epidemiology Center estimates and South Dakota Department of Health, *Pregnancy-Associated and Infant Deaths in SD: 2012-2021* (November 2023).
6. E. Arias et al., National Vital Statistics System, *Provisional Life Expectancy Estimates for 2021*, Vital Statistics Rapid Release Report no. 23 (September 30, 2022).
7. *Frequently Asked Questions*, Bureau of Indian Affairs, U.S. Department of the Interior, available at <<https://www.bia.gov/frequently-asked-questions>> (last visited November 21, 2023).
8. See, for example, Meriam, *supra* note 1, and United States Government Accountability Office, *Indian Health Service: Actions Needed to Improve Oversight of Provider Misconduct and Substandard Performance*, Report to Congressional Requesters, GAO-21-97 (December 10, 2020).
9. U.S. Commission on Civil Rights, *A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country*, Report to Congress (July 2003).
10. D.H. Getches et al., *Cases and Materials on Federal Indian Law, 7th Edition*, (Eagan, MN: West Academic Publishing, 2017): at 32.
11. *Id.*
12. See GAO Report, *supra* note 3.
13. Indian Health Care Improvement Act § 1621m(b); Indian Health Care Improvement Act § 1621m(e)(1).
14. See IHCA, *supra* note 13.
15. National Indian Health Board, *Public Health in Indian Country Capacity Scan Report 2019*, (2020).
16. U.S. Commission on Civil Rights, *Broken Promises: Continuing Federal Funding Shortfall for Native Americans*, Briefing Report (December 2018).
17. See GAO Report, *supra* note 3.
18. See GAO Report, *supra* note 3: at *Recommendations*.
19. *Id.*
20. See National Indian Health Board, *supra* note 15.
21. *What is Electronic Case Reporting?* (September 18, 2023), Centers for Disease Control and Prevention, U.S. Department of Health and Human Services, available at <<https://www.cdc.gov/ecr/what-is-ecr.html>> (last visited November 20, 2023).
22. See Broken Promises report, *supra* note 18: at 2.
23. See Quiet Crisis report, *supra* note 9: at 13.
24. C.P. Jones, “Systems of Power, Axes of Inequity: Parallels, Intersections, Braiding the Strands,” *Medical Care* 52 (2014): S71–S75, available at <https://journals.lww.com/lww-medicalcare/Fulltext/2014/10001/Systems_of_Power_Axes_of_Inequity__Parallels.12.aspx> (last visited November 21, 2023).