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Centering Data Sovereignty, Tribal Values, and Practices for Equity in American Indian and Alaska Native Public Health Systems

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Abstract

As the first scientists on the American continents, American Indian and Alaska Native people followed various methodologies in the pursuit of knowledge to understand and respond to complex environmental situations.¹ Examples include data necessary to guide access to safe food and medicine as well as community roles, kinship, travel, housing, and healing for the well-being of the community. These Tribal data have been transmitted through specific practices with strict protocols such as storytelling, songs, and ceremony. Colonialism and attempts to eradicate Tribal cultures have stolen or at the very least hidden most of the original Tribal data practices in all current public health systems.² Current methodologies fail to accurately capture data on American Indian and Alaska Native populations, resulting in inaccurate and even harmful data outcomes. Efforts to improve public health data systems should begin with the reclamation of Tribal knowledge systems and the reconstruction of these systems to fit our modern context and Tribal data sovereignty, with intentionality toward future generations.

Keywords

American Indian and Alaska Native; public health; data systems; sovereignty

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Background

Tribal sovereignty is the inherent authority of a Tribe to govern and protect the health, safety, and welfare of Tribal citizens.^{3,4} As sovereign entities, Tribes establish their government structure; define citizenship; make and enforce laws about Tribal lands, environment, education, culture, and health; manage associated data through their own systems; and interface with surrounding data systems. American Indian and Alaska Native populations comprise 574 distinct US-recognized and more than 60 state-recognized sovereign Tribal nations in the United States.^{3,5}

Tribal data sovereignty is the right to ownership and governance of the collection and use of Tribal data.⁶ Tribal data sovereignty and Tribal data governance are powerful tools to improve the accuracy and relevance of data that represent Tribal circumstances, customs, and worldviews.⁷ However, data on American Indian and Alaska Native people are captured not only within Tribal data systems but also across local, state, federal, and international data systems in places where American Indian and Alaska Native people live.

In 2021, the COVID-19 pandemic and the Centers for Disease Control and Prevention's declaration of racism as a public health crisis⁸ spurred national action, including the Robert Wood Johnson Foundation's convening of the National Commission to Transform Public Health Data Systems (the Commission). The Commission was charged with reimagining how data are collected, shared, and used and identifying public and private sector investments needed to improve health equity.⁹ In April 2021, a panel of American Indian and Alaska Native public health data experts from diverse Tribal backgrounds (hereinafter, panel), all with decades of experience in public health data systems—including current and former Tribal and federal employees, academics, and public health practitioners—convened in 8 hours of virtual meetings during 3 sessions to inform the Commission.⁹ The panelists discussed issues with public health data systems and offered recommendations for improvement.

The panel's recommendations centered on the many long-standing challenges and inadequacies of American Indian and Alaska Native data across all levels of government, research, and practice.¹⁰ The panel highlighted the need and opportunities for investment in infrastructure to improve interoperability of data systems across several disciplines (eg, criminal justice, education, environment, human services) that interface with American Indian and Alaska Native public health data, along with the need for improved capacity among those managing data on American Indian and Alaska Native people.

This commentary provides additional context for understanding public health data collection and analysis as they relate to American Indian and Alaska Native communities, as well as the unique challenges associated with them. It also shows how understanding the data equity of American Indian and Alaska Native people is a crucial piece of health equity. Tribal sovereignty, along with critical shifts in the recognition and inclusion of Tribal knowledge systems, data sovereignty, and community values, is key to transforming public health data and systems across all governments. This commentary also describes how models such as

the Medicine Wheel, the Becoming Butterfly framework, and other approaches rooted in Tribal teachings are working to conceptualize metrics for health and well-being in American Indian and Alaska Native communities.

Public Health Data Systems

Public health data are necessary to identify, respond to, and mitigate public health threats, but the data are often held by non-Indigenous governments and institutions and are not always representative of or available to American Indian and Alaska Native public health systems. Federal, state, and local governments have not consistently upheld or supported Tribes' rights to access data,¹¹ and Tribes are not always fully integrated into their surveillance systems, other public health data systems, or networks.¹² Without real-time access to accurate 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 prevention and other public health interventions. A national report card of state-by-state efforts for American Indian and Alaska Native COVID-19 data details myriad data equity issues.¹³ Prevailing challenges stem from lack of interoperability, insufficient funding, power imbalance, and lack of consensus on Tribal sovereignty and public health authority roles. Opportunities and challenges exist at the interface of Tribal and external government systems.¹⁴

Tribal and urban American Indian public health systems are a fairly recent part of the US public health system, as they were established in the 1970s as part of Tribal self-governance legislation.¹⁵ The American Indian and Alaska Native public health system also includes the establishment of 12 regional Tribal Epidemiology Centers in the 1990s by the Centers for Disease Control and Prevention, National Institutes of Health, and Indian Health Service.¹⁶ Tribal Epidemiology Centers offer public health data services with authorization to request and use Tribal, local, state, and federal public health data, although according to a 2022 US Government Accountability Office study, problems with data access persist.¹⁷

Government-to-government consultation advances Tribal data sovereignty and can lead to improvements in how data are collected, tabulated, analyzed, interpreted, and reported, consistent with Tribal laws and code, policies, procedures, and preferences. Government agencies with data on American Indian and/or Alaska Native people have a responsibility to engage in government-to-government consultation with Tribes and urban Native communities through a US federal mechanism called Tribal Consultation and/or Urban Confer.¹⁸ On January 26, 2021, President Biden signed a Presidential Memorandum reaffirming Executive Order 13175, which directs federal agencies to “engage in regular, meaningful, and robust consultation with Tribal officials in the development of federal policies that have Tribal implications” (ie, Tribal Consultation and/or Urban Confer), hence encompassing American Indian and Alaska Native data and data systems.¹⁸ While Tribal Consultation and/or Urban Confer policies offer some solutions for federal-level American Indian and Alaska Native data, Tribal access to quality state-level data correlates with the quality of Tribal–state relations.

Key demographic variables such as race (single, multiple), ethnicity, Tribal affiliation/enrollment, open-ended variables, residency, age, and gender identity all require clear and defined terminology and definitions to accurately reflect the population. Tribal engagement will guide partners in the best use of demographic variables such as Tribal enrollment, American Indian and Alaska Native in combination with multiple races, or Latinx/Hispanic ethnicity versus American Indian and Alaska Native alone.¹⁹

For example, American Indian and Alaska Native can be defined in several ways for data analysis. However, terms such as *Native American* or *Indigenous* are not specific enough to describe the unique legal standing of American Indian and Alaska Native people who are members of federally recognized Tribes in the United States. The minimum data standards of the US Department of Health and Human Services and Office of Management and Budget detail the use of a consistent race definition of “American Indian and Alaska Native” across federal and state data systems as a solution developed in consultation with Tribes.^{20,21} Common definitions can support accurate and meaningful data disaggregation, which decision makers need to understand public health needs and resource allocation.

Problems in mainstream public health data systems include racial misclassification, aggregation, and refusal to share public health data with Tribal public health agencies.²² In many areas, American Indian and Alaska Native people are a small part of the population, resulting in suppression or aggregation of data in broad categories such as “multiracial” or “other.”²³ Linkage projects that cross-reference American Indian and Alaska Native data with Tribal registries prevent racial and ethnic misclassification and are critical to improve the quality of American Indian and Alaska Native data.^{24–26}

Upholding Tribal data sovereignty and improving American Indian and Alaska Native public health data systems require action beyond the consultation and conferral process. Inclusion of and consultation with American Indian and Alaska Native people, governments, and organizations in all aspects of these data systems improve accuracy and relevance of data. Relationship building and effective communication among all partners are critical to ensure effective American Indian and Alaska Native data systems and Tribal data governance.^{27–29}

The Collective Benefit, Authority to Control, Responsibility, and Ethics (CARE) principles are a framework for centering Indigenous data sovereignty that works across multiple settings to support joint decision-making by Indigenous and non-Indigenous public health authorities.³⁰ White et al³¹ illustrated the application of CARE principles in Tribal public health research. Using the CARE framework, Tribal public health partners can bring culturally based understanding of data to discussions with partners and identify the strengths and limitations of proposed research methodologies when advising on public health data collection and analyses.

As the American Indian and Alaska Native panel noted in its recommendations to the Commission, health infrastructure and capacity vary across Tribal and urban partners, with real needs for sustainable investment in public health infrastructure, such as broadband internet access, data capacity, and workforce, and interoperable data solutions built to advance American Indian and Alaska Native health.¹⁰

Tribal public health authority is the basis for government-to-government relations and data sharing with other public health authorities at the federal, state, and local levels. Public health authorities are defined as “[A]n agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an Indian Tribe . . . responsible for public health matters as part of its official mandate.”³² This authority is documented in the Health Insurance Portability and Accountability Act.³² In addition, in an effort to improve Tribal data access, the US government designated Tribal Epidemiology Centers as public health authorities in the 2010 permanent reauthorization of the Indian Health Care Improvement Act.³³

Tribal public health systems exercise sovereignty through intergovernmental agreements with local, state, and federal public health systems as well as with other Tribes and inter-Tribal organizations, such as Tribal Epidemiology Centers, to define and communicate public health authority on public health functions and data responsibilities. These agreements clarify the designation of specific authorities, such as surveillance and information systems and the acquisition, use, disclosure, and storage of identifiable health information, and strengthen Tribal data sovereignty and opportunities for authentic engagement.¹⁴ Pervasive challenges in data sharing and data access can be mitigated through formal agreements between Tribes and state and local public health entities. NativeDATA is a new online resource with practical guidance for sharing American Indian and Alaska Native public health data among public health authorities.³⁴

Tribal Data Practices

Outside these public health systems, American Indian and Alaska Native people continue to uphold the tradition of data collection to ensure the health and well-being of the community. For generations, data keepers have used oral tradition, objects, prayer, and artistic expression to disseminate knowledge to the succeeding keepers of the data. Data remain “embedded in storytelling and cultural principles, and [are] transmitted orally or recorded through winter counts, song, ceremony, calendar sticks, totem poles, buffalo hides, and other physical objects.”³⁵ Tribal ways of knowing are often misrepresented, overlooked, or extracted and misappropriated because of colonial and misogynistic ideologies, systemic racism, and misappropriation that permeate institutional public health data and research.³⁶

The movement toward data equity gives rise to a need to revitalize these practices in Tribal communities. The restoration of cultural values of spirituality, prayer, relationship, and collectivism that are inclusive of community voices, including elders and young people, is at the core of American Indian and Alaska Native data systems and data practices.³⁷

We have to ask if our public health data and systems are measuring and reporting what really matters. American Indian and Alaska Native health is centered on the collective community rather than on individual illness or well-being. Individual-level measurements do not reflect the health of the community, yet aggregated individual data are consistently used to compare American Indian and Alaska Native populations with other races.³⁶

The Medicine Wheel is a commonly used model that represents holistic health across physical, mental, emotional, and spiritual dimensions. The model is widely accepted and understood across Tribes, many of which have detailed their unique teachings and language through this model.³⁸ Another example is the Becoming Butterfly framework, based on a Tribal model of healing, which proposes a community-centered, public health approach to transform American Indian and Alaska Native health systems through the use of an adapted performance management model to improve health.³⁹

American Indian and Alaska Native public health practitioners are working to conceptualize metrics for determinants of health and well-being that resonate with the community, reflect culture and traditions, and provide meaningful insight into local experiences. Other Tribal models of health and well-being exist. For example, the Swinomish Indian Tribe's model has metrics that reflect the Tribe's values, teachings, and ways of life as a community, with measures tied to the health of water, land, and animals and data on spiritual and cultural connections such as language and sacred sites.⁴⁰ The Native Coast Salish communities developed and pilot tested a set of Indigenous health indicators that reflect Tribal health (community connection, natural resources security, cultural use, education, self-determination, and resilience).⁴¹

Public Health Implications

Public health authorities need relevant and accurate data from within and across public health systems to identify, manage, and evaluate the well-being of American Indian and Alaska Native populations. Available morbidity and mortality data provide evidence on the devastating health inequities experienced by American Indian and Alaska Native populations. However, these data must move us toward asking more questions—not to admire the problems but to find solutions. What is missing from the data? What are the stories hidden in the data? Data outcomes are improved when data are grounded in the history and current cultural context of American Indian and Alaska Native people and Tribal nations.

Public health data are most useful when they reflect realities and the strengths of a people. American Indian and Alaska Native well-being is grounded in community values and in Tribal teachings and ways of life that have supported resilience for millennia, such as ceremonies, traditional roles and responsibilities, and rites of passage; clearly, these are protective factors. Other examples of potentially relevant protective factors include Tribal language fluency and use of traditional foods and medicines. Examining data related to these teachings may provide meaningful insights on the well-being of American Indian communities.³⁶

National investments in state-level public health transformation and data modernization encourage the full integration of Tribal public health systems with local and state public health systems.⁴² Most state and local governments determine which limited public health functions will be managed by the Tribe. However, with new public health investments and an eye toward equity and Tribal sovereignty, some Tribes are exercising sovereignty and

determining which public health data functions are best managed internally and when it makes sense to rely on state and local government systems.

Promising examples from the Public Health National Center for Innovations' 21C Learning Community indicate how state health departments are focused on strengthening partnerships across Tribal, state, and local public health jurisdictions to create a cohesive statewide public health system.⁴² For example, Tribes in Oregon and Washington have been working to integrate with one another for more than 5 years and offer examples of reciprocal partnerships and data agreements between state and local public health agencies. The Northwest Portland Area Indian Health Board convened Tribal leaders across Oregon to review the state's health assessment system and develop recommendations to improve methods and data quality for Tribes.⁴³ The recommendations included supporting Tribes to conduct their own Tribal Behavioral Risk Factor Surveillance System survey to improve relevance, participation, and data protections.⁴³ In Washington State, Tribes are defining how the state's public health services funding and delivery framework will apply to Tribal public health and how Tribal public health will work with state and local health jurisdictions.⁴⁴ These processes support strengthened Tribal sovereignty while establishing Tribal public health data codes and policies and communicating appropriate roles through inter-agency and data-sharing agreements.

Recommendations

Tribes advance their sovereignty when Tribal public health systems reflect Tribal teachings and values; therefore, Tribal public health leaders are encouraged to move beyond a deficit-based view to a strength-based public health approach and engage diverse community voices to identify public health data that center Tribal values and are relevant to community well-being. The following recommendations are for all public health professionals striving to improve American Indian and Alaska Native public health data equity across governmental public health authorities.

- Build relationships and effective communication among all partners.
- Establish ongoing Tribal formal data-sharing agreements.
- Recognize Tribal sovereignty and Tribal data systems and data practices as valid and central to Tribal data sovereignty.
- Identify public health data that are relevant to community well-being and community needs.
- Define key demographic variables such as race, ethnicity, Tribal affiliation/enrollment, residency, and gender identity.
- Determine appropriate categories for data aggregation in partnership with American Indian and Alaska Native partners.
- Invest in linkage projects that cross-reference American Indian and Alaska Native data with Tribal registries to prevent racial and ethnic misclassification.

- Invest in public health infrastructure, such as broadband internet access, data capacity, and workforce, and interoperable data solutions.

Conclusion

American Indian and Alaska Native health equity begins with critical shifts in the centering of Tribal knowledge, community values, and data sovereignty as key components of transforming public health systems. Tribal public health leaders are working to strengthen public health infrastructure and capacity and establish roles to advance American Indian and Alaska Native data and health equity to measure the well-being of American Indian and Alaska Native people in our modern context. As Tribal public health systems reclaim Tribal data sovereignty and Tribal data governance, they are developing culturally centered indicators to be integrated with all public health data systems. Public health leaders can positively contribute to American Indian and Alaska Native public health data and overall well-being by approaching the work with an understanding of Tribal sovereignty.

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