SEATTLE INDIAN HEALTH BOARD

Systemic Inequities in Indigenous Data Governance

Addressing Institutional Barriers to Public Health Data Access between the Centers for Disease Control and Prevention and Tribal Epidemiology Centers

Seattle Indian Health Board and our research division, Urban Indian Health Institute (UIHI), are committed to understanding the impacts of coronavirus disease 2019 (COVID-19) in urban American Indian and Alaska Native communities. As an Indian Health Service (IHS)-designated Tribal Epidemiology Center and public health authority, UIHI supports the epidemiology needs of urban Indian communities in 62 urban areas nationwide.

Congressional authorization allows Tribal Epidemiology Centers to access to Health and Human Services (HHS) data as a public health authority. While the Centers for Disease Control and Prevention (CDC) has recently agreed to release COVID-19 surveillance data to UIHI, institutional barriers in accessing the National Notifiable Disease Surveillance System (NNDSS) and related public health data persist. A failure to grant timely and consistent data access perpetuates systemic health inequities in American Indian and Alaska Native communities. Analysis of NNDSS data and other CDC collected COVID-19 data is critical to supporting tribal and urban Indian organizations as they prevent, prepare, and respond to the current and second surge of COVID-19 cases.

Understanding Tribal Epidemiology Centers and their Authorities

Most data on urban American Indian and Alaska Native populations are collected and maintained by non-Indigenous entities including city, county, state, and federal public health entities. To address fragmented data systems, Tribal Epidemiology Centers, have been granted public health authority status to access relevant state- and county-level data collected by HHS.

Tribal Epidemiology Centers need access to NNDSS and other CDC-collected COVID-19 datasets to prevent, prepare, and respond to COVID-19. Tribal and urban Indian communities are planning for both current and future surges of COVID-19. Like other local health jurisdictions, these communities must be equipped with the right information to prepare the healthcare and public health system's response using data-driven decision-making.

The public health authority status of Tribal Epidemiology Centers must be honored. Tribal Epidemiology Centers are best positioned to advise and lead the appropriate collection and analysis of American Indian and Alaska Native data. To fully operate as public health authorities alongside local, state, and federal entities, the statutory roles and authorities of Tribal Epidemiology Centers must be upheld.

Recommendations

To address the institutional barriers to public health data access, Seattle Indian Health Board recommends Congressional partners:

Mandate U.S. states to enter into data sharing agreements that ensure American Indian and Alaska Native data is accessible to tribes and Tribal Epidemiology Centers as public health authorities.

Leverage Congressional oversight authority to ensure HHS agency compliance with data sharing requirements.

Extend the IHS Urban Confer policy to all HHS agencies to encourage mutual understanding and strengthen relationships between HHS agencies and urban Indian organizations.

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About Tribal Epidemiology Centers

There are twelve Tribal Epidemiology Centers designated by the Indian Health Service. Nationwide, 11 Tribal Epidemiology Centers operate regionally to serve tribal nations, and one operates nationally to serve urban Indian organizations. Tribal Epidemiology Centers were granted public health authority with the permanent reauthorization of the Indian Health Care Improvement Act (IHCIA) in Title X Part III of the Patient Protection and Affordable Care Act.

About Public Health Authorities

Indian tribes and Tribal Epidemiology Centers are Public health authorities alongside agencies or authorities of the United States government, a State, a territory, or a political subdivision of a State or territory that is responsible for public health matters as part of its official mandate. This includes a person or entity acting under a grant of authority from, or under a contract with, a public health agency.[1]

About Urban Confer Policies

IHS is the only federal agency with an Urban Confer policy. Urban Confer policies allow for an open and free exchange of information and opinions that leads to mutual understanding and comprehension, and emphasizes trust, respect, and shared responsibility[2] between federal agencies and urban Indian organizations. These policies do not substitute for nor do they invoke the rights of a tribal nation, rather they allow urban Indian organizations to represent the needs of urban American Indian and Alaska Native people as an Indian Health Care Provider.

[1] 45 CFR §164.501 Subtitle A (10–1–04 Edition)

[2] Indian Health Service. Indian Health Manual: Ch. 26 - Conferring with Urban Indian Organizations. Retrieved from: https://www.ihs.gov/ihm/pc/part-5/p5c26/. Accessed (2020).