

Tribal Health Data Improvement Act

Senator Tina Smith (D-Minn) and Senator Lisa Murkowski (R-AK)

American Indian and Alaska Native (AI/AN) communities face stark health disparities across multiple health conditions including diabetes, cancer, liver disease, and kidney disease. Despite these alarming health inequities, public health surveillance data systems at the Federal, State, and local levels indicate high rates of missclassification and undersampling of AI/ANs. This contributes to an underestimation of disease burden in AI/AN communities. In addition to inaccurate AI/AN health data, Tribes face significant challenges in accessing data at the Federal, State, and local levels to correct for these and other data accuracy problems.

Under federal law, Tribal governments and Tribal Epidemiology Centers (TECs) are designated as “public health authorities.” This allows Tribes and TECs to access public health surveillance data at the Federal, State and local levels for public health purposes. In practice, however, Tribes are routinely denied access to health data systems, limiting their ability to exercise their public health authority and address issues in data quality. During COVID-19, Tribes have faced significant challenges in accessing CDC data to carry out their duties as sovereign nations, and continue to be disproportionately impacted by the pandemic. Many States are not reporting AI/AN-specific COVID-19 data altogether, further contributing to the invisibility of health conditions impacting AI/ANs among the mainstream public.

The bipartisan *Tribal Health Data Improvement Act* would help alleviate many of these challenges and strengthen relations between Tribes and CDC to effectively address public health challenges for Native communities. **The *Tribal Health Data Improvement Act* would:**

- Require the Department of Health and Human Services to give direct access to public health data to Tribes, the Indian Health Service, and Tribal Epidemiology Centers
- Require the Centers for Disease Control and Prevention (CDC) to develop guidance for States and local health agencies to improve the quality and accuracy of birth and death record data for American Indians/Alaska Natives
- Require the CDC to enter into cooperative agreements with Tribes, Tribal organizations, urban Indian organizations, and Tribal Epidemiology Centers to address misclassification and undersampling of American Indians/Alaska Natives on birth/death records and in health care/public health surveillance systems
- Encourage states to enter into data sharing agreements with Tribes and Tribal Epidemiology Centers to improve access to public health data

Endorsed by: National Indian Health Board (NIHB), National Council of Urban Indian Health (NCUIH), Seattle Indian Health Board, American Academy of Pediatrics