National Indian Health Board

March 5, 2024

Jess Smith, Acting Director
Office of Intergovernmental and External Affairs
U.S. Department of Health and Human Services
Hubert Humphrey Building
200 Independence Avenue S.W.
Mail Stop: 620-E
Washington, DC 20201

RE: HHS Tribal and Tribal Epidemiology Center Data Access Policy

Dear Ms. Smith:

On behalf of the National Indian Health Board (NIHB), I write to you regarding draft U.S. Department of Health and Human Services (HHS) Tribal And Tribal Epidemiology Center Data Access Policy. As currently written, the draft policy fails to adequately fulfill any of its stated objectives or address the recommendations from the Government Accountability Office that prompted the creation of a data access policy. If HHS is to implement a data access policy that reinforces Tribal sovereignty, provides clarity on concepts and processes, and eliminates barriers to data access for Tribes and Tribal Epidemiology Centers (TECs), the policy must be fundamentally rewritten.

HHS could bring significantly more clarity to the issues by creating separate policies for Tribes versus TEC data access. The legal basis for each of their authority to access health data differ significantly, and so too do the accompanying issues and concerns. Importantly, a Tribe is inherently a public health authority. A Tribe does not need to "create" a public health authority in order to exercise its inherent authority to carry out public health functions. A Tribal data access policy need only explain once that Tribes are Public Health Authorities and thereon refer only to "Tribes." Every additional unnecessary complexity the policy introduces has the potential to become one more obstacle in the way of access to life-saving data. "Upon request by a PHA created by a Tribe," for example, may be incorrectly and problematically interpreted to mean the Tribe must first create a specific public health entity before the Tribe can receive data. Separate policies for Tribes and TECs will allow space to make distinctions between the two cases, eliminate unnecessary phrases and undue complications, and clarify how HHS will meaningfully improve access to data for each.

The policy furthermore inappropriately introduces conditions to data sharing that undermine both Tribal sovereignty and the intent of the Indian Health Care Improvement Act in requiring the sharing of data

with Tribal Epidemiology Centers. Qualifiers such as "to the extent feasible" and "as permitted" by "existing agreements" pepper the policy throughout. If existing agreements do not respect Tribal sovereignty, they are faulty and need to be amended. This draft policy will clearly serve only to uphold the status quo – a status quo in which essential health data is delayed from reaching Tribes, and which federal reports have cited as contributing to preventable deaths of American Indians and Alaska Natives.

The issues cited here are only a few examples of the multitude of problems featured in the draft HHS Tribal and Tribal Epidemiology Center Data Access Policy. During Tribal consultation, multiple Tribal leaders stated that HHS needs to "go back to the drawing board" and draft new data sharing policies – plural, to separate the issue of Tribal access from that of TEC access. We urge HHS to heed this call and to efficiently draft new policies that will fully respect Tribal sovereignty and take real steps to improve data access rather than uphold the current unjust status quo. Tribes must be meaningfully included in the process of drafting the new policies to ensure they will avoid falling into the same pitfalls as the current draft. HHS has a significant opportunity to drive health equity through policy change – but the new policy must require operating divisions to change how they do business as usual, or the same problems will continue.

Yours in Health,

Stacy A. Bohlen, Sault Ste. Marie Chippewa
Chief Executive Officer
National Indian Health Board