

February 6, 2024

Violet Woo Designated Federal Officer Advisory Committee on Minority Health Office of Minority Health, United States Department of Health & Human Services Tower Building 1101 Wootton Parkway, Suite 100 Rockville, M.D. 20852

Re: HHS Implementation of OMB Race and Ethnicity Data Collection Standards

### Dear Violet Woo:

On behalf of the <u>National Indian Health Board</u> (NIHB), I write to you regarding the U.S. Department of Health and Humans Services (HHS) implementation of the updated race and ethnicity data collection standards. In consideration of the federal trust responsibility, Tribal sovereignty, and the harmful history of data being weaponized against American Indians and Alaska Natives, HHS must take special care to consider these unique complexities while implementing updated data standards and proceed only through meaningful, timely, robust Tribal consultation.

## I. THE NATION-TO-NATION RELATIONSHIP

# Federal Trust Responsibility

The United States has a unique legal and political relationship with Tribal governments, established through and confirmed by the U.S. Constitution, treaties, federal statutes, executive orders, and judicial decisions. Central to this relationship is the federal government's trust responsibility: a legal obligation to protect the health and wellbeing of American Indians and Alaska Natives (AI/ANs). Timely, accessible, high quality health data are essential for Tribes to be able to protect their citizens. The federal government therefore has a responsibility to improve data standards, policies, and practices to enhance data quality and accessibility to Indian health care providers and Tribal public health authorities. HHS's implementation of the new race and ethnicity data standards will greatly influence the quality of data that exists for AI/AN and its accessibility to Tribes.

#### Tribal Consultation

Tribes are sovereign nations with the authority and responsibility to protect the health and wellbeing of their citizens. As sovereign equals, the United States maintains a government-to-government relationship with all federally recognized Tribal nations. This means the United States must work directly with Tribes in all governmental functions concerning Indian Country. Given that the implementation of the updated race and ethnicity data standards will have a significant impact on Tribes and Tribal citizens, **HHS must hold Tribal consultation on the implementation of the new standards**, as required by Executive Order 13175, President Biden's memoranda on *Tribal Consultation and Strengthening Nation-to-Nation Relationships*, and *Uniform Standards for Tribal Consultation*.



50 F Street, NW | Suite 600 | Washington, DC 20001 | 202-507-4070 | www.nihb.org



#### II. DATA SOVEREIGNTY

To address cross-cutting data issues for AI/ANs, data collectors from any HHS operating division must recognize and respect Tribal data sovereignty. Tribes must have a say in how their data is used and who sees it. Before data that involves Tribes is reported publicly, Tribes must be consulted on what data gets collected and reported and how it is displayed. In addition, any data about Tribal citizens must be shared back with the Tribe. Alongside ongoing Tribal consultation, the principles of data sovereignty must guide all work that HHS undertakes involving data, including the implementation of the new race and ethnicity data standards.

## III. FOLLOW BEST PRACTICES FOR AI/AN DATA COLLECTION

High quality race data is essential for Tribes to understand the impacts of important health issues on Tribal communities, but data quality issues currently surround the accuracy and completeness of race information for AI/ANs. Quality race data is essential for Tribal public health authorities to protect AI/AN health through identifying trends and emerging concerns, setting priorities, and responding quickly and effectively to public health emergencies. Undercounts of AI/AN population impede these health-protecting activities, as well as impeding important funding from reaching Tribal communities when the data is not available to show the full extent of the need or enhance Medicaid access. To protect Tribal data sovereignty, reduce risk of harm, and improve data quality, HHS should adhere to Best Practices for AI/AN Data Collection and provide guidance and tools to swiftly and uniformly implement the updated standards across operating divisions and state health agencies.

## IV. CAREFUL DATA REPORTING TO REDUCE RISK OF HARM

In creating any analysis or report which includes race as a variable, data users must take extreme care to consider and communicate what "race" means in that context and take steps to mitigate risk of harm. Reports that single out a Tribe or a race with high rates of a stigmatized health condition, for example, can contribute to further stigmatization of that community and further entrench health inequities. Frequently, "race" is used as a proxy variable for "experiences of racism." In addition, uniquely for American Indians and Alaska Natives, "AI/AN" is first and foremost a political status – an identifier of those who are party to the unique trust relationship with the United States. However, this information is still collected under the "race" question. Multiracial and Hispanic AI/ANs are frequently excluded from counts of AI/AN population, despite still being party to the political trust relationship. Given these complexities, serious risk of harm exists if race data is used carelessly. HHS must require that all data analyses and reports involving AI/AN: 1) undergo Tribal consultation; 2) acknowledge AI/AN as a political status; 3) include all AI/AN alone or in combination with other races/ethnicities; and 4) make clear that racism, and not race, is the driver of health disparities correlated with the race variable.

As HHS moves towards implementing the revised OMB standards for race and ethnicity data collection, timely, meaningful, and robust Tribal consultation is critical to protect Tribal data sovereignty, reduce risk of harm, and advance health equity for American Indians and Alaska Natives.

Yours in Health,

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