

October 25, 2024

The Honorable Xavier Becerra  
Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Re: HHS Tribal Data Access Policy and HHS Tribal Epidemiology Center Data Access Policy

Dear Secretary Becerra:

On behalf of the physician and medical student members of the American Medical Association (AMA), I appreciate the opportunity to offer our comments to the U.S. Department of Health and Human Services (HHS) on the HHS Tribal Data Access Policy and HHS Tribal Epidemiology Center (TEC) Data Access Policy.

The AMA supports HHS issuing guidance on public health and Tribal-affiliation data sharing with American Indian and Alaska Native (AI/AN) Tribes, Villages, and Tribal Epidemiology Centers.<sup>1</sup> We commend the creation of both the Tribal Data Access Policy as well as the TEC Data Access Policy and believe they will foster greater Tribal sovereignty over their own data, allowing Tribes to make informed, data-driven decisions that directly impact their health and well-being.

Poor data collection and reporting standards implemented by states have left significant gaps in understanding how COVID-19 disproportionately impacted people of color across the U.S., particularly for AI/AN people.<sup>2</sup> For example, AI/AN populations were more likely to contract COVID-19 and experience severe outcomes.<sup>3,4</sup> In 2020, the Centers for Disease Control and Prevention's Morbidity and Mortality Weekly Report found that lab-confirmed COVID-19 cases were 3.5 times higher among AI/AN persons compared to non-Hispanic white individuals. However, this analysis was limited to data from just 23 states, each with more than 70 percent complete race/ethnicity information.<sup>4</sup> This lack of comprehensive data obscured the full extent of the burden AI/AN communities faced and hindered the ability of local, state, federal, territorial,

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<sup>1</sup> H-350.950 Tribal Public Health Authority | AMA. Accessed October 15, 2024. <https://policysearch.ama-assn.org/policyfinder/detail/Tribal%20Public%20health%20Authority%20H-350.950?uri=%2FAMADoc%2FHOD.xml-H-350.9950.xml>.

<sup>2</sup> Urban Indian Health Institute (2021) Data Genocide of American Indians and Alaska Natives in COVID-19 Data. Seattle, WA: Urban Indian Health Institute.

<sup>3</sup> Musshafen LA, El-Sadek L, Lirette ST, Summers RL, Compretta C, Dobbs TE. In-Hospital Mortality Disparities Among American Indian and Alaska Native, Black, and White Patients With COVID-19. *JAMA Netw Open*. 2022;5(3): e224822. doi:10.1001/jamanetworkopen.2022.4822.

<sup>4</sup> Hatcher SM. COVID-19 Among American Indian and Alaska Native Persons — 23 States, January 31–July 3, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69. doi:10.15585/mmwr.mm6934e1.

and Tribal public health authorities (PHAs) to address the disproportionate impacts of COVID-19.<sup>2</sup> Additionally, it limited policymakers' capacity to make data-driven decisions for equitable policies and adequate resource allocation.

The AMA has been working to advance an interoperable health care ecosystem with an eye toward ameliorating disparities using granular data segmentation—in other words, preserving trust while sharing data. We co-founded Shift<sup>5</sup> to advance granular data segmentation standards and implementation guidance. Shift is an independent health care task force of over 250 expert stakeholders that envisions a world of safe, equitable, and patient-empowered sharing of health information.

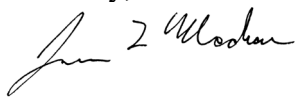
Lacking adequate tools for granular segmentation of sensitive data, health care organizations resort to imprecise automated or manual processes to withhold sharing for broad patient populations. This can result in care inequities and the potential for information blocking. Lacking trust in data protection, patients with stigmatized conditions will be less likely to consent to having their data shared. As sensitive conditions are more prevalent in historically minoritized and marginalized populations, this can contribute to health disparities. Patients have the right to withhold specific sensitive data, due to state and/or federal law. In other instances, a patient's living situation, culture or values, relationships, or other expressed needs may warrant a clinician withholding health information.

We encourage HHS and Tribes to advance policies that will reaffirm how the Department will provide Tribes with data (both in general and when acting in their capacities as PHAs), including the scope of data available, the process to obtain data, and the expected timelines for processing Tribal requests for data, while investigating opportunities around granular data segmentation to preserve trust while sharing data. The HHS-wide expectation should be to respond to requests from Tribes for data in the custody and control of HHS and its staff and operating divisions. By improving and clarifying how the Department will provide data to Tribes, HHS can advance health equity for AI/AN people and eliminate data disparities facing Tribes.

The AMA stands behind the HHS Tribal Data Access Policy and the HHS TEC Data Access Policy. We commend the Administration for its continuing commitment toward improving data access and health outcomes for Tribal communities.

Thank you for considering the AMA's comments. If you have any questions, please feel free to contact Margaret Garikes, Vice President, Federal Affairs, at [margaret.garikes@ama-assn.org](mailto:margaret.garikes@ama-assn.org) or 202-789-7409.

Sincerely,



James L. Madara, MD

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<sup>5</sup> Shift. Accessed October 22, 2024. <https://www.drummondgroup.com/shift/>.