

National Indian Health Board



National Indian Health Board Resolution 20 – 04

Resolution to Call upon the National Institutes of Health to Consult with Tribal Nations and Establish Policies and Guidance for Tribal Oversight of Data on Tribal Citizens Enrolled in the *All of Us* Research Program

WHEREAS, the National Indian Health Board (NIHB), established in 1972, serving all federally recognized American Indian/Alaska Native (AI/AN) Tribal governments by advocating for the improvement of health care delivery to AI/ANs, as well as upholding the federal government's Trust Responsibility to AI/AN Tribal governments, does hereby establish and submit the following resolution; and

WHEREAS, the National Institutes of Health (NIH), a part of the U.S. Department of Health and Human Services, is the nation's medical research agency, and researchers funded by NIH have made important discoveries that have the potential to improve health and reduce health disparities; and

WHEREAS, the NIH established the *All of Us* Research Program to recruit one million or more people in the United States to improve health through precision medicine, which involves the collection of data and biospecimens from individuals to understand differences in lifestyle, environment, and biology, including analysis of genetic data; and

WHEREAS, American Indians and Alaska Natives (AI/ANs) have significant health disparities, such as an average life expectancy that is 5.5 years lower than that of the general United States population, that the findings of research could help address, but are often overlooked and not represented in research studies; and

WHEREAS, Tribal Nations are political, sovereign entities whose status stems from the inherent sovereignty they possess as self-governing people predating the founding of the United States, and since its founding the United States has recognized them as such and entered into treaties with them on that basis; and

WHEREAS, Tribal Nations have inherent sovereign rights to govern research that occurs with their citizens and on their lands, and are concerned that past negative experiences with research may continue to impact their nations; and

WHEREAS, in many cases, Tribal Nations have established Tribal research codes, laws, and research oversight processes to govern research to ensure it benefits their nations and reduces risks of harm to their communities; and

WHEREAS, Tribal Nations have a unique government-to-government relationship with the federal government, and it is required that the federal government consult with Tribal Nations on any policy or action that will significantly impact Tribal governments and AI/ANs; and

WHEREAS, the NIH does not have a Tribal consultation policy but follows the U.S. Department of Health and Human Services Tribal Consultation Policy, updated in 2010; and

WHEREAS, at the request of Tribal Nations, the NIH initiated a Tribal consultation on the *All of Us* Research Program on May 24, 2019, requesting input on how to “develop meaningful, culturally appropriate collaborations with AI/AN populations” and how to identify “priorities and opportunities around the inclusion of AI/AN populations in the research program while also implementing the appropriate protections to comply with Tribal research oversight and laws;” and then subsequently held consultation and listening sessions with Tribal Nations in various locations during the summer of 2019; and

WHEREAS, NIHB wrote a comment in October 2019 to NIH expressing disappointment in the lack of transparency, slowness of pace, and the overall piecemeal approach with which the agency has adopted Tribal suggestions throughout the consultation periods; and

WHEREAS, the NIH Tribal Advisory Committee recently approved a motion to extend the Tribal consultation by two months to allow for more input and discussion with Tribal Nations, and also requested to review the recommendations of the All of Us Research Program Tribal Collaboration Working Group, which is not a part of the Tribal consultation process; and

NOW THEREFORE BE IT RESOLVED, that the National Indian Health Board (NIHB) calls on the NIH to continue Tribal consultation on the *All of Us* Research Program to allow for more meaningful discussions and input; and

BE IT FURTHER RESOLVED, that NIHB calls on NIH to work closely with the NIH Tribal Advisory Committee to assess consultation input to date and immediately develop clear processes and guidelines that ask individual sovereign Tribal Nations to provide prior consent before collecting data and specimens from their Tribal members, and provide Tribal Nations oversight, including local control and storage of any data or biospecimens that are associated with or identified to be from a citizen of their Tribal nation; and

BE IT FURTHER RESOLVED, that all data collected on AI/AN individuals and data identified to be associated with specific Tribal Nations must be restricted from any research use until Tribally developed and approved oversight processes and guidelines are adopted by the NIH *All of Us* Research Program; and

BE IT FURTHER RESOLVED, that the NIH send any draft final processes and guidelines to Tribal Nations for consultation and input prior to being finalized and implemented; and

BE IT FINALLY RESOLVED, that this resolution shall be the policy of NIHB until it is withdrawn or modified by subsequent resolution.

CERTIFICATION

The foregoing resolution was adopted by the Board, with quorum present, on the 26th day of February, 2020.

Victoria Kitcheyan

Chairperson, Victoria Kitcheyan

ATTEST:

Lisa Elzin

Secretary,