



NATIONAL CONGRESS OF AMERICAN INDIANS

**The National Congress of American Indians
Resolution #ABQ-19-061**

TITLE: Calling 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

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WHEREAS, we, the members of the National Congress of American Indians of the United States, invoking the divine blessing of the Creator upon our efforts and purposes, in order to preserve for ourselves and our descendants the inherent sovereign rights of our Indian nations, rights secured under Indian treaties and agreements with the United States, and all other rights and benefits to which we are entitled under the laws and Constitution of the United States and the United Nations Declaration on the Rights of Indigenous Peoples, to enlighten the public toward a better understanding of the Indian people, to preserve Indian cultural values, and otherwise promote the health, safety and welfare of the Indian people, do hereby establish and submit the following resolution; and

WHEREAS, the National Congress of American Indians (NCAI) was established in 1944 and is the oldest and largest national organization of American Indian and Alaska Native tribal governments; 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, American Indians and Alaska Natives (AI/ANs) have significant health disparities that the findings of research could help address, but are often overlooked and not represented in research studies; 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 some 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, 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, 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

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 held consultation and listening sessions with tribal nations in various locations during the summer of 2019; and

WHEREAS, NIH in its May 24, 2019 letter initiating tribal consultation “welcomed written testimony” by August 31, 2019, and then issued a Request for Information (RFI) on September 3, 2019, to solicit “additional input to the *All of Us* Research Program 2019 Tribal Consultation” that allows input from the public “for information and planning purposes” which is not a mechanism that is used in the U.S. Department of Health and Human Service Tribal Consultation Policy and does not represent a government-to-government form of consultation; 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

WHEREAS, both NCAI and the United South Eastern Tribes sent letters to the NIH Director and the *All of Us* Research Program in September 2019 requesting an extension to the timeline of the tribal consultation and more information and clearer timelines on how the NIH plans to respond to the tribal consultation.

NOW THEREFORE BE IT RESOLVED, that the National Congress of American Indians (NCAI) calls on the NIH to continue the *All of Us* Research Program tribal consultation to allow for more meaningful discussions and input; and

BE IT FURTHER RESOLVED, that NCAI 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 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 tribal 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 NCAI until it is withdrawn or modified by subsequent resolution.

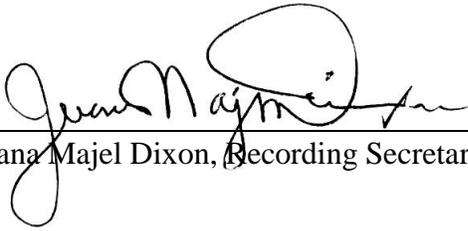
CERTIFICATION

The foregoing resolution was adopted by the General Assembly at the 2019 Annual Session of the National Congress of American Indians, held at the Albuquerque Convention Center, October 20-25, 2019, with a quorum present.



Fawn Sharp, President

ATTEST:



Juana Majel Dixon, Recording Secretary