

National Institutes of Health Bethesda, Maryland 20892

September 24, 2020

Dear Tribal Leader or Urban Indian Organization Leader:

We recognize that American Indian/Alaskan Native (AI/AN) communities are facing tremendous hardships as a result of the COVID-19 pandemic. We aim to continue advancing biomedical research to improve health outcomes for the future of all AI/AN communities. As you may recall, last April NIH announced plans to work in partnership with Tribal Nations to solicit input on NIH's proposed data management and sharing policy efforts¹. We are pleased to share with you the attached final report from this Tribal Consultation and update you on NIH's plans for implementing activities in response to Tribal leaders' recommendations.

NIH specifically acknowledges the historic experiences and harms related to data oversight and privacy concerns of AI/AN populations and strives to partner with Tribal Nations to inform responsible research practices. Moreover, NIH recognizes Tribal sovereignty and is committed to soliciting input in accordance with the *HHS Tribal Consultation Policy*² and the *NIH Guidance on the Implementation of* <u>the HHS Tribal Consultation Policy</u>³. Following these policies, NIH initiated the 2019 Tribal Consultation on a new policy proposal for the management and sharing of data resulting from NIH-funded or conducted research. Specific details of the Tribal Consultation process and outcomes are outlined in the Tribal Consultation report that concludes the Consultation process. We encourage you to share this report broadly across your community. It will also be provided publicly at <u>https://osp.od.nih.gov/scientific-sharing/engaging-tribal-nations/.</u>

NIH supports the recommendations received through Tribal Consultation and intends to emphasize the role of Tribal sovereignty in a future data management and sharing policy. To supplement the policy, NIH intends to develop and disseminate guidance that promotes research partnerships between researchers, Tribal Nations, and urban AI/AN communities and helps researchers respectfully manage and share data. Through this guidance, NIH will work to educate researchers on best practices for ethical data management and sharing, along with strategies for mitigating potential risks to AI/AN communities.

NIH is committed to building partnerships with Tribal Nations. We are deeply appreciative for the thoughtful dialogue and engagement of Tribal leaders in this important topic and hope this will be the first of many productive conversations in the future. Ultimately, working together to enhance trust, we can increase AI/AN representation in biomedical research which will lead to improved health outcomes for Tribal communities.

Sincerely yours,

Carrie D. Wolinetz, Ph.D Acting Chief of Staff and Associate Director for Science Policy, NIH

¹ <u>https://dpcpsi.nih.gov/sites/default/files/NIH_Dear_Tribal_Leader_Letter-Data_Sharing_Management_508.pdf</u>

² https://www.hhs.gov/sites/default/files/iea/tribal/tribalconsultation/hhs-consultation-policy.pdf

³ <u>https://dpcpsi.nih.gov/thro/policy</u>