November 2, 2023

Dear Tribal Leader and Urban Indian Organization Leader:

I am writing from the National Institute on Aging (NIA), part of the National Institutes of Health under the U.S. Department of Health and Human Services, to initiate a Tribal Consultation and Urban Confer on the Alzheimer's Disease (AD) and other types of dementia Real-World Data Platform, to be held on **January 5, 2024, at 2:00 p.m. EST.** I hope that you will be able to participate in this discussion to help ensure input representing American Indians and Alaska Natives on this critical effort to improve health outcomes for older adults, persons living with dementia, and their families.

Despite the passage of the National Alzheimer's Project Act in 2011, and increases in funding, there is still an incomplete (although increasing) understanding of the underlying mechanisms contributing to dementia, and there are few FDA-approved treatments. Transforming and accelerating the dementia research enterprise requires addressing one of the most prevalent and costly problems in dementia research: lack of data accessibility and links between complementary data sources that capture information from larger, more inclusive, and diverse populations.

The Real-World Data Platform, led by NIA, is designed to provide a transformative approach to this problem by creating a data infrastructure that will serve as a resource to dementia researchers, including American Indian/Alaska Native (AI/AN) scientists, while honoring Tribal sovereignty and Tribal Data ownership and respecting and protecting the privacy of individuals and communities whose data are included in the databases. The Platform will provide a secure, central hub of access for many types of data collected from a variety of sources, including pharmacies; electronic health records; medical and dental claims; sensor data from things like smartwatches and smartphones, wearables, and internet-connected medical devices; and social, environmental, and biological determinants of health data. Increasing accessibility and usability of this set of data through the Platform may lead to the development of high-impact, scalable interventions to improve health outcomes for older adults and persons with dementia, while reducing participant burden and incorporating cultural perspectives into research, interpretation, and dissemination.

The Real-World Data team is seeking your input at this early stage to thoughtfully incorporate feedback in the Platform's design and planning. We value the opportunity to learn how this Platform might advance the goals and strategic priorities of AI/AN Tribes, to demonstrate that the questions and data generated are relevant for AI/AN communities, to identify potential risk factors and effective community- and individual-level interventions, and to generate knowledge useful to AI/AN communities and health care providers.

Participant Information:

What: Tribal Consultation on the NIA Real-World Data Platform
Date: Friday, January 5, 2024
Time: 2:00–4:00 p.m. EST | 1:00–3:00 p.m. CST | 12:00–2:00 p.m. MST | 11:00 a.m.–1:00 p.m. PST | 10:00 a.m.–12:00 p.m. AKST | 9:00–11:00 a.m. HST
Join: Please register for the webinar at the link

For technical meeting questions related to connectivity or audio/visual matters, please contact Evan Serge at evan.serge@nih.gov.

If you are unable to attend, we invite you to send written testimony, comments, or questions to NIHTribalConsultation@nih.gov by **February 20, 2024**.

If you have any additional questions, please feel free to contact the NIA Real-World Data Planning Committee at NIARWD@nih.gov.

Thank you for your continued partnership as we work together to improve the health of American Indians and Alaska Natives. We look forward to this opportunity to listen and learn from you.

Sincerely,
Richard J. Hodes, M.D.
Director, National Institute on Aging