DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health Bethesda, Maryland 20892 www.nih.gov

May 1, 2023

Dear Tribal Leader and Urban Indian Organization Leader:

The National Institutes of Health's <u>All of Us Research Program</u> invites you to a series of four *All of Us* Tribal virtual informational presentations and discussions. Following these informational sessions, *All of Us* will host a Tribal consultation on September 28, 2023. *All of Us* is a landmark health research program that aims to find more precise ways to improve health for all populations through individualized prevention, treatment, and care.

From May to October 2019, *All of Us* held its <u>first Tribal consultation</u> to hear input from Tribal leaders and Tribal-serving organizations about engaging with Tribal Nations and the inclusion of American Indian and Alaska Native (Al/AN) individuals into this program. As a result, we learned more about how we can support research in ways that protect and respond to the needs of participants and Al/AN communities.

In response to Tribal consultation, recruitment and engagement on Tribal lands has been prohibited while the program developed a Tribal engagement plan to support program commitments to Tribes and incorporated Tribal priorities, such as Tribal data sovereignty, cultural sensitivity and awareness, Al/AN-specific policies, training and education, data protections, research transparency, and the return of information to Tribal communities.

As *All of Us* partner networks grow across the country, we want Tribal leaders to be aware of *All of Us* engagement and outreach activities through our enrollment partners and that Tribal citizens may encounter advertising materials off Tribal lands in hospitals, community centers, libraries, mobile engagement trailers, etc. Please note, we are not recruiting by Tribe or on Tribal lands. Additionally, we want to keep Tribes well-informed about the program and welcome the opportunities to meet with Tribal Nations and Al/AN urban organizations to discuss details about the program and to learn more about the possible benefits of participating.

The program will host a series of virtual informational presentations and discussion on the following topics:

- Session 1: All of Us Research Program Overview and Tribal Engagement Tuesday, June 6, 2023, from 1:00 – 3:00 pm ET
- Session 2: How Researchers Access and Use All of Us Data Tuesday, June 13, 2023, from 1:00 – 3:00 pm ET

- Session 3: Describing Self-Identified Al/AN Participants in All of Us Data Tuesday, June 20, 2023, from 1:00 – 3:00 pm ET
- Session 4: Data and Partnerships in All of Us Tuesday, June 27, 2023, from 1:00 – 3:00 pm ET

Please register through the link at allofus.nih.gov/TribalEngagement

The informational presentations and discussion do not constitute or replace formal tribal consultation; rather, it is an opportunity for attendees to learn more about the *All of Us* Research Program and for the program to continue our ongoing dialogue and engagement with Tribal, rural, and urban Al/AN communities.

At the end of the series, *All of Us* will host a formal Tribal consultation on Tribal engagement efforts being developed that are important to Tribes. The consultation will include an update on our approach to Tribal engagement and discussion about integrating information from self-identified Al/AN participants in our data platform, the *All of Us* Research Hub. A federal register notice will be published announcing the consultation.

We hope you will join us for the informational presentations and discussion and Tribal consultation. The *All of Us* Research Program believes that Tribal engagement is driven by meaningful discussion and feedback from Tribal Leaders, and we are working to ensure our efforts are rooted in full recognition of the sensitivity around data access, use, and protection.

You may send your questions and written testimony about these topics to AOUTribal@nih.gov. Please submit your written testimony for Tribal consultation on Tribal letterhead by October 26, 2023, with the subject line "All of Us Tribal consultation written response". For more information on our Tribal engagement activities, please visit the All of Us Tribal Engagement site at allofus.nih.gov/TribalEngagement.

Thank you for your continued partnership as we work together toward improving the health of American Indian and Alaska Native peoples through research.

Sincerely,

Joshua Denny, MD, MS Chief Executive Officer All of Us Research Program National Institutes of Health

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