

Continued *All of Us* Updates for Leaders of Tribal Nations and Urban Indian Organizations — January 2024

Executive Summary

January 26, 2024

Dear Tribal Leader and Urban Indian Organization Leader:

The National Institutes of Health's *All of Us* Research Program aims to accelerate health research and medical breakthroughs to enable an era of precision medicine for all. *All of Us* is committed to ensuring the program reflects the diversity of the United States, including American Indian and Alaska Native (AI/AN) and Indigenous communities, while respecting Tribal sovereignty.

On September 28, 2023, *All of Us* hosted a virtual Tribal consultation on management of self-identified AI/AN data, Tribal engagement and outreach, and program planning activities. Comments were accepted from June 28, 2023, to October 28, 2023. We would like to thank each of the Tribal leaders and Tribal partners who added to the discussion and submitted recommendations.

A summary of all written testimony and comments is now available online in the [2023 *All of Us* Research Program Tribal Consultation Report](#). Several recurring themes emerged: 1) the importance of continued consultation and dialogue between Tribes and NIH, 2) concerns about AI/AN self-identification, 3) oversight of researchers' use of AI/AN data, 4) researcher training, 5) utilization of Tribes' Institutional Review Boards, and 6) consideration of Tribal diversity. In the report, *All of Us* provides responses to all comments, with information about specific steps the program is taking.

In response to concerns about the oversight of research with AI/AN data, the program has expanded its governance bodies with additional AI/AN representation and expertise. *All of Us* also has developed new tools to help reinforce policies for researchers regarding AI/AN research materials. With these augmented measures and layers of oversight in place, *All of Us* plans to incorporate data from self-identified AI/AN participants into the Researcher Workbench with the next data release, which is currently planned for late 2024.

The program will continue partnering with Tribal Nations and Indigenous communities for responsible and community-led participation through its ongoing [funding opportunity](#), which awarded \$1.5 million to partners collaborating with Tribal communities.

All of Us is committed to strengthening its relationships with Tribes and will use feedback from consultation to guide ongoing Tribal engagement efforts. The program will continue to provide updates to Tribal Advisory Committees and seeks to support additional consultation, partnership agreements, and research opportunity awards. Should you have any questions, please reach out to us at AOUTribal@nih.gov or visit AllofUs.nih.gov/TribalEngagement for more information.

Sincerely,

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