

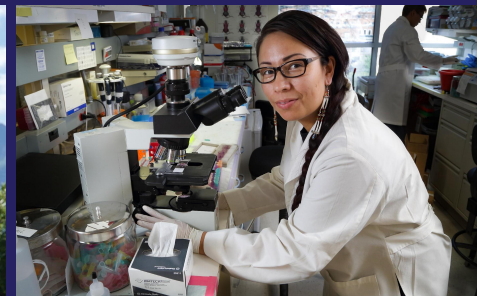
# All of Us Research Program Update

## TAC Meeting 8/16/2023

**All**  
*of* **Us**  
RESEARCH PROGRAM

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Chief Executive Officer, *All of Us* Research Program



# Goals for today

- **Announce** new Tribal Engagement partner award
- **Highlight** four virtual informational sessions from June 2023
- **Overview** of topics and questions for Sept 28th *All of Us* Tribal Consultation and seek input on framing questions to Tribes.
  - Management and Sharing of Self-Identified AI/AN Data Without Tribal Affiliation
  - Tribal Engagement and Outreach
  - Program Planning Activities
- **Seek TAC's guidance** on approaches to engage Tribes in our next Consultation to advance program mission in collaboration with sovereign Tribal Nations

# Increasing Capacity to Support Tribes and *All of Us* Tribal Engagement

- Program award: University of Arizona
  - **Purpose:** Conduct community readiness assessments with potential Tribal partners to determine their readiness to participate in *All of Us*
  - **Outcome:** Development of a strategic plan for long-term Tribal Engagement for *All of Us* and future partnership with Tribes
  - **Award amount:** \$300K/yr
  - **Year 1 performance period:** July 1, 2023- July 1, 2024
- **Anticipate two additional Tribal Engagement awards in 2023**



[Research Opportunity Announcement \(ROA\): NIH All of US Engagement, Communications, and Enrollment Partnerships](#)

# *All of Us* Tribal Engagement: Informational Sessions and Tribal Consultation

- **June 6-27, 2023:** Four virtual sessions held to inform, establish relationships with AI/AN and Indigenous communities and provide the opportunity to engage with the program. Slides and recordings available online.
  - Discussion themes included:
    - Conducting outreach to Tribal leaders and communities
    - Building capacity and research infrastructure in Tribal communities
    - Complexities of AI/AN self-identification in research
    - Data collection within Tribal communities
    - Tribal partnerships
- **August 11, 2023:** HHS Region-10 Tribal Consultation
  - *All of Us* leadership invited to join THRO for the NIH session

## All of Us Tribal Consultation

- NIH *All of Us* will host our next Tribal consultation virtually on **Thursday, September 28, from 1:00 - 3:00 pm ET**
- **Topics:**
  - **Current policies/protections for AI/AN data**
  - Outreach efforts where **zip codes** overlap with Tribal land
  - **Data access expansion** to future inclusion of international and industry researchers
  - Future inclusion of **children of AI/AN participants** in the program
  - Input on traditional **blessing ceremony** for AI/AN participants who withdraw from the program
- Register at <https://allofus.nih.gov/TribalEngagement>
- If preferred, Elected Tribal Officials are encouraged to submit written testimony on Tribal letterhead to [AOUTribal@nih.gov](mailto:AOUTribal@nih.gov) by October 28, 2023.

# Discussion of Next *All of Us* Tribal Consultation: Approach and Topics

**Emerging Topics:** How can we best consult with Tribal leaders on these developing parts of the program?

- **Pediatrics:** What unique considerations are there for the future inclusion of AI/AN infants, children, and adolescents as participants in the program, given that a child's parent or legal guardian must be a current participant?
  - Are there additional considerations for family-based enrollment in *All of Us* (e.g., parent or legal guardian participating with their child)?
- **Researcher Access Expansion:** What kinds of protective practices and measures can be implemented to avoid infringing upon Tribal sovereignty when collecting or working with individual participant data?
  - What additional considerations would you recommend for training and access to de-identified data for researchers from international and industry sectors?

# All of Us Resources for Tribal Advisory Committee

[All of Us Program Overview \(joinallofus.org\)](https://joinallofus.org)

[Tribal Engagement Website](#)

## 2023 Updates

[May 1, 2023 Dear Tribal Leader Letter](#)

- Highlighted information sessions and announced Sept 28 Tribal Consultation

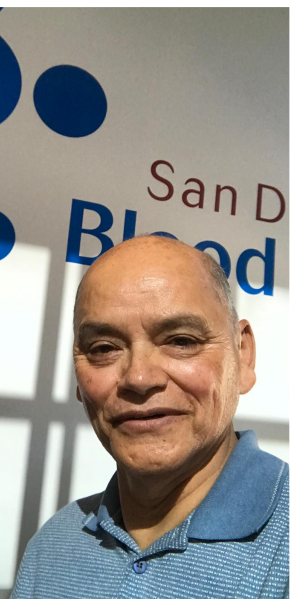
[June 2023 Information Sessions: Slides and Recordings](#)

[June 28, 2023 Federal Register Notice](#)

- Notice To Announce Tribal Consultation for an *All of Us* Research Program Update and To Discuss the Program's Policies and Protections Around Data Access and Use ([2023-13750.pdf](#))

[July 21, 2023 Dear Tribal Leader Letter](#)

- Highlighted upcoming Tribal Consultation and future researcher access expansion, including those from international academic, not-for-profit, and health care organizations and industry.



**Thank you!**

@AllofUsResearch  
@AllofUsCEO  
#JoinAllofUs



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**Thank you to our 689,000+ participants!**