



June 30, 2021

Dear Tribal Leader and Urban Indian Organization Leader:

We are writing to initiate virtual Tribal Consultation on a proposed idea for a National Institutes of Health (NIH) Tribal Data Repository (TDR) to house COVID-19 data. We are seeking your input on key issues that are critical to the creation of this resource, including how the data repository can recognize Tribal sovereignty and include appropriate governance to maximize Tribal access and participation.

In response to the Tribal Consultation for COVID-19 Research<sup>1</sup> held in May 2020, NIH incorporated Tribal input into the design of the **Rapid Acceleration of Diagnostics (RADx) Initiative**<sup>2</sup> meant to accelerate the development, commercialization, and implementation of COVID-19 testing. RADx for **Underserved Populations (RADx-UP)**<sup>3</sup> has specifically focused on understanding and developing approaches to improve health outcomes and reduce disparities for populations who are disproportionately affected by the pandemic. RADx-UP supports interlinked community-engaged research projects to enable and enhance COVID-19 testing. It also supports research that assesses how ethical, historical, social, economic, and cultural factors influence willingness to be tested for COVID-19 infection.

We are needing your input on how to shape a Tribal Data Repository's ability to hold and share Tribal data. The TDR is envisioned to be a central research data repository resource for researchers and their collaborators who are generating or interested in working with Tribal RADx research data. The TDR is intended to be a tribally directed and governed data repository that will collaborate with the RADx-UP Collaboration and Data Collection Center (RADx-UP CDCC)<https://radx-up.org> to:

- Support data collected by RADx projects conducted in Tribal communities
- Facilitate responsible sharing of de-identified Tribal research data to researchers to address scientific questions concerning testing and vaccination for COVID-19 and other pandemic research
- Enable and support current and future basic and applied research
- Build Tribal capacity for 'big data' research by supporting pre- and post-doctoral mentored fellowships for AI/AN students.

Suggested questions for your consideration:

- How should the TDR be established to incorporate and sustain tribal sovereignty for data collected and stored?
- What are your expectations for data ownership and stewardship?
- What are your expectations for data governance and data access?
- What are your expectations for sustainability of the RADx-TDR once the initial RADx Initiative has ended?
- What is your guidance to address data ownership, stewardship, and governance issues for rural, urban, or non-reservation dwelling individuals who self-identify as American Indian/Alaska Native?

<sup>1</sup> Tribal Consultation for COVID-19 <https://dpcpsi.nih.gov/thro/tribal-consultations/covid-19>

<sup>2</sup> Rapid Acceleration of Diagnostics (RADx) Initiative <https://www.nih.gov/research-training/medical-research-initiatives/radx>

<sup>3</sup> Rapid Acceleration of Diagnostics Underserved Populations (RADx-UP) Program <https://radx-up.org>

In accordance with the NIH's implementation of the U.S. Department of Health and Human Services (HHS) Tribal Consultation Policy, NIH is announcing a one-hour virtual **NIH Tribal Consultation on Tribal Data Repository** on Friday, July 30, 2021 at 2:00 p.m. – 3:00 p.m. EDT. We encourage you to participate in this discussion. A pre-consultation Tribal Data Repository (TDR) informational webinar will be held on Tuesday, July 20, 2021 at 2:00 p.m. – 3:00 p.m. EDT.

**Participant information:**

**What:** NIH Tribal Consultation on Tribal Data Repository

**Date:** Friday, July 30, 2021

**Time:** 2:00-3:00 PM EDT | 1:00-2:00 PM CDT | 12:00-1:00 PM MDT | 11:00-12:00 PM PDT | 10:00-11:00 AM AKDT

**Live videocast link:** <https://nih.zoomgov.com/j/1605667744>

If you have any technical questions related to connectivity or audio/visual matters regarding the meeting, please contact Vivian OTA WANG at [otawangv@nih.gov](mailto:otawangv@nih.gov). If you are unable to attend, you are encouraged to send testimony and comments to [NIHTribalConsultation@nih.gov](mailto:NIHTribalConsultation@nih.gov) by July 30, 2021.

The NIH remains committed to continuing its efforts to improve relations with Tribal Nations, and to partnering with Tribal Nations to use the power of biomedical research to support healthier communities. For more information, please contact Dr. David Wilson, Director of the NIH Tribal Health Research Office, at: [NIHTribalCommittee@od.nih.gov](mailto:NIHTribalCommittee@od.nih.gov).

Thank you for your continued partnership as we work together during this public health emergency to improve the health of American Indians and Alaska Natives. We look forward to this opportunity to listen and learn from you about the potential for a Tribal Data Repository for COVID-19. If you have any additional questions, please feel free to contact:

Dr. Vivian OTA WANG  
Office of Data Science Strategy  
Division of Program Coordination, Planning, and Strategic Initiatives  
Office of the Director  
E-mail: [otawangv@nih.gov](mailto:otawangv@nih.gov)

Dr. Dorothy Castille  
Division of Scientific Programs  
National Institute on Minority Health and Health Disparities (NIMHD)  
E-mail: [dorothy.castille@nih.gov](mailto:dorothy.castille@nih.gov)

Sincerely,

Susan Gregurick, Ph.D.  
Associate Director for Data Science  
Director, Office of Data Science Strategy  
Division of Program Coordination, Planning and Strategic Initiatives  
Office of the Director

Eliseo J. Pérez-Stable, MD  
Director, National Institute on Minority Health and Health Disparities