

National Institutes of Health (NIH) Tribal Consultation on a Tribal Data Repository for COVID-19 Research

Tuesday, July 30, 2021 | 2:00 – 3:00 p.m. EDT

This document provides an overview for Tribal leaders and community members to participate in the upcoming ***NIH Tribal Consultation on a Tribal Data Repository for COVID-19 Research*** as a web-based meeting on Friday, July 30, 2021, 2:00 – 3:00 p.m. EDT.

National Institutes of Health (NIH)

NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.

- NIH invests nearly \$50.54 billion¹ annually in medical research for the American people.
- More than 80% of NIH's funding is awarded through almost 50,000 competitive grants to more than 300,000 researchers at more than 2,500 universities, medical schools, and research institutions in every state.
- About 10% of the NIH's budget supports projects conducted by nearly 6,000 scientists in its own laboratories, most of which are on the NIH campus in Bethesda, Maryland.
- Located in Bethesda, Maryland, the NIH is a component of the U.S. Department of Health and Human Services and is composed of the Office of the Director and 27 Institutes and Centers, many of which have an organ- or disease-specific focus. The Office of the Director is the central office at NIH and is responsible for setting policy for NIH and for planning, managing, and coordinating the programs and activities of all the NIH components.

Purpose of Consultation

NIH is focused on supporting research and projects that can increase our overall understanding of COVID-19 and its effects on American Indians/Alaska Natives (AI/AN and their communities. As NIH accelerates its research efforts, it is critical that the agency seeks Tribal input on efforts to address the needs of AI/AN communities. The input heard at this consultation will be used to inform the NIH of how to shape a Tribal Data Repository's ability to hold and share Tribal data.

¹ This amount includes discretionary budget authority of \$50.54 billion, Program Evaluation financing totaling \$1.27 billion, and slightly over \$140 million for mandatory special type 1 Diabetes research. The total request also includes \$6.50 billion for an Administration initiative to create a new Advanced Research Project Agency for Health (ARPA-H). Visit the links on the Budget Request for more information on the NIH request.

COVID-19 Research Efforts

Urgent public health measures continue to be needed to control the spread of the novel coronavirus (SARS-CoV-2) or COVID-19. Importantly, scientific research to improve our understanding of the virus and the diseases it causes, and to develop strategies to mitigate illness and death is urgent and of paramount importance.

In response to the May 2020 Tribal Consultation for COVID-19 Research², NIH incorporated Tribal input into the **Rapid Acceleration of Diagnostics (RADx) Initiative**³ meant to accelerate the development, innovation, commercialization, and implementation of COVID-19 testing. RADx for **Underserved Populations (RADx-UP)**⁴ has specifically focused on understanding and developing approaches to improve health outcomes and reduce disparities for populations who are disproportionately affected by the pandemic. Specifically, RADx-UP supports interlinked community-engaged research projects to enable and enhance COVID-19 testing. It also supports research that assesses how ethical, historical, healthcare, social, economic, and cultural factors influence the willingness to be tested for COVID-19 infection.

Tribal Data Repository

The establishment of a Tribal Data Repository (TDR) is being planned by the RADx-Initiative. 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
- Provide a pathway to build capacity for big data research skills for Tribal scholars through pre- and post-doctoral mentored fellowships.

During this consultation, the NIH seeks your input on how to shape a Tribal Data Repository's ability to hold and share Tribal data.

Suggested questions for 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?

² Tribal Consultation for COVID-19 <https://dpcpsi.nih.gov/thro/tribal-consultations/covid-19>

³ Rapid Acceleration of Diagnostics (RADx) Initiative <https://www.nih.gov/research-training/medical-research-initiatives/radx>

⁴ Rapid Acceleration of Diagnostics Underserved Populations (RADx-UP) Program <https://radx-up.org>

- 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?