

December 1, 2023

Dear Tribal Leader and Urban Indian Organization Leader:

The National Institutes of Health (NIH) launched the Rapid Acceleration of Diagnostics (RADx) initiative to accelerate the development, commercialization, and implementation of COVID-19 testing. We are writing to inform you of an important and exciting development—the establishment of the RADx Tribal Data Repository: Data for Indigenous Implementations, Interventions, and Innovations (D4I). The goal of the RADx Tribal Data Repository is to support and facilitate responsible data storage, data sharing, and data access for researchers and their collaborators who are generating or are interested in working with RADx data provided by American Indian and Alaska Native research participants, including data for COVID-19 and other health topics collected under RADx projects.

After competitive review, Stanford University in partnership with the Native BioData Consortium have been selected to lead this unique NIH-supported effort. The Native BioData Consortium is the first Indigenous led 501(c)(3) nonprofit research organization and biodata repository within the geographic borders and legal jurisdiction of a Tribal Nation (Cheyenne River Sioux Tribe). Selected activities of the RADx Tribal Data Repository will include catalyzing Tribal data initiatives through ongoing engagement of Tribal Nations; establishing best practices for responsible data sharing and access through engagement and consultation of RADx Tribal partners; and constructing a secure, centralized Tribal Data Repository for collection and harmonization of de-identified data from American Indian and Alaska Native persons. The Native BioData Consortium will also build research capacity through construction of analytic spaces for Tribal use and education resources for emerging American Indian and Alaska Native scholars and communities.

The RADx Tribal Data Repository was the result of input from the Tribal Consultation on COVID-19 Research in May 2020 and the Tribal Consultation on RADx Tribal Data in July 2021, as well as collaborative efforts among the NIH Office of Data Science Strategy, National Institute on Minority Health and Health Disparities, and NIH Tribal Health Research Office. There is a collective commitment to ensuring that the knowledge generated by the RADx initiative is disseminated and implemented in meaningful ways, while also respecting Tribal sovereignty and Tribal data ownership.

The RADx Tribal Data Repository will serve as a resource to facilitate data-informed understanding and subsequent decisions to support policy development in addressing the multiple impacts of the COVID-19 pandemic in Indian Country. In addition, this groundbreaking project has the potential to serve as a model for other communities affected by health disparities and can inform Tribal and public health boards and governmental agencies on promising approaches to address future health challenges.

The RADx Tribal Data Repository reflects NIH's commitment to partner with Tribal Nations on responsible data sharing, honor Tribal ownership of the data, and data sovereignty, as well as to use the power of biomedical, social sciences, and behavioral research to support healthier American Indian and Alaska Native communities.

Sincerely,

A handwritten signature in black ink, appearing to read "Eliseo J. Pérez-Stable". The signature is fluid and cursive, with the first name "Eliseo" being more prominent.

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

Co-Chair, RADx-UP Initiative

A handwritten signature in black ink, reading "Susan Gregurick". The script is fluid and cursive, with the first name "Susan" being more prominent than the last name "Gregurick".

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

A handwritten signature in black ink, reading "Karina Walters". The script is fluid and cursive, with the first name "Karina" being more prominent than the last name "Walters".

Karina L. Walters, Ph.D., M.S.W. (Choctaw Nation of Oklahoma)
Director, Tribal Health Research Office
Division of Program Coordination, Planning, and Strategic Initiatives
Office of the Director