2019 National Institutes of Health (NIH) Tribal Consultation
on
Data Sharing and Management for NIH Funded or Supported Research

This document was prepared to aid tribal leaders and community participants in the upcoming NIH Tribal Consultation on the development of NIH Data Sharing and Data Management Policy, June 20, 2019, Sacramento, California, July 15-18, in Washington, DC, and August 20-22, in Denver, CO.

National Institutes of Health (NIH)
NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the applications of that knowledge to enhance health, lengthen life, and reduce illness and disability.

- The NIH invests nearly $37.3 billion[1] annually in medical research for the American people.

- More than 80% of the 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 other research institutions in every state around the world.

- The NIH is composed of 27 Institutes and Centers (https://www.nih.gov/institutes-nih) of which many have an organ- or disease-specific focus, and the Office of the Director, which is responsible for setting policy and planning, managing, and coordinating NIH programs and activities.

NIH has a responsibility to maintain stewardship over taxpayer funds by making the results and accomplishments of the research that it funds and conducts available to the public. In NIH's view, data should be made as widely and freely available as possible while safeguarding the privacy of participants and protecting confidential and proprietary data.

Increasing access to scientific data resulting from NIH funding or support offers many benefits. Specifically, sharing scientific data and results enables researchers to more vigorously test the validity of research findings, strengthen analyses by combining data sets, access hard-to-generate data, and explore new frontiers. Data sharing also informs future research pathways, increases the return on investment of scientific research funding, and accelerates the translation of research results into knowledge, products, and procedures to improve health and prevent disease. Effective data sharing practices rely upon appropriate identification, adoption, and tracking of good data management and sharing practices, that permit data sharing consistent with the FAIR (Findable, Accessible, Interoperable, and Re-usable) data principles.

- In 2015, NIH released its Plan for Increasing Access to Scientific Publications and Digital Scientific Data from NIH Funded Scientific Research (https://grants.nih.gov/grants/NIH-Public-Access-Plan.pdf).

- To help NIH establish priorities for data management and sharing, NIH in 2016 released a Request for Information on Strategies for NIH Data Management and Sharing, and in 2017 co-hosted with the National Science Foundation a joint workshop, focused on the value of data sharing.(https://grants.nih.gov/grants/guide/notice-files/NOT-OD-17-015.html)
- Public input from these events, and formal consultation with Tribes, will help to inform NIH's development of key provisions for a future NIH policy for the management and sharing of data, which would replace the 2003 NIH Data Sharing Policy.

Some suggested questions:

- Who owns the data collected from Tribal communities?
- How can Tribes be assured that unethical use of data is limited?
- Who controls access to Tribal data?
- At what point was the tribal consultation initiated in the NIH plan for data sharing?
- Has a meta-analysis been done to identify best practices for use of data from datasets that can be sorted by race?
- Update on the RFI and where those recommendations area
- Restricting access to those with significant ethics trainings?
- What will occur if Tribal leaders do not want data to be shared?
- In case investigator bush up with the rules.
- Training for working with these policy collaborations
- What if Tribal leaders don't want data to be shared but individual Tribal members do want data shared.
- Would NIH agree to Tribal approval to any release of data for AI/ANs?
- Strategy for confirming minimal risk to human subjects when data is shared