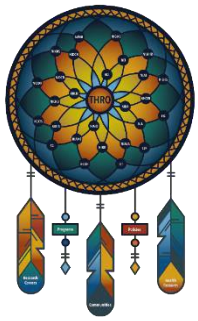

Tribal Health Research Office

Division of Program Coordination, Planning, & Strategic Initiatives
Office of the Director, National Institutes of Health

NIH Data Management and Sharing Policy Development

Why is sharing biomedical research data important?

- Data sharing advances science by promoting rigorous research, reducing unnecessary duplication of studies, and enabling new research questions to address important health challenges.
- Sharing taxpayer funded research increases public trust in science and promotes accountability for how funds are spent.
- Effective data sharing maximizes research participants' volunteer contributions to science and ensures diverse representation in research.

What are some challenges to managing and sharing research data?

- Good data management and sharing practices require time, effort, and money to ensure data are sufficiently protected, shared, and usable.
- Research participants are sometimes concerned about how data are made available to investigators outside of the research study.
- Researchers are often not rewarded for sharing data and can lack infrastructure to easily do so.

What should a future NIH data management and sharing policy look like?

- NIH is committed to crafting a policy that fosters a culture of responsible data sharing and clearly communicates NIH's expectations for policy adherence.
- NIH's strategy is to implement a flexible framework for researchers to describe how they plan to manage and share data resulting from their research.
- A future policy would build upon NIH's existing policy framework, including informed consent, Human Subjects Protections, Certificates of Confidentiality, etc., and include consideration of exceptions to sharing where appropriate.

How can Tribal communities work with NIH?

- NIH's mission is to improve health through research; engagement with the Tribal Nations is key in building partnerships to best serve these communities' priorities and needs in pursuit of this goal.
- NIH is seeking input from Tribal communities on key considerations that should be included in a future NIH policy for promoting responsible data management and sharing, while safeguarding stakeholders' needs.

- Feedback received through the Tribal consultation and other public engagement efforts will result in a data management and sharing policy that fosters biomedical research for all.

Data Sharing Resources

- 2003 NIH Data Sharing Policy: https://grants.nih.gov/grants/guide/notice-files/NOT-OD-03-032.html
- 2013 OSTP Memorandum: Increasing Access to the Results of Federally Funded Scientific Research: https://obamawhitehouse.archives.gov/sites/default/files/microsites/ostp/ostp_public_access_memo_2013.pdf
- NIH Plan to Increase Access to Scientific Data and Publications: https://grants.nih.gov/grants/nih-public-access-plan.pdf
- NIH Policy for Issuing Certificates of Confidentiality: https://grants.nih.gov/grants/guide/notice-files/NOT-OD-17-109.html
- NIH Proposed Provisions for a Future Draft Data Management and Sharing Policy: https://osp.od.nih.gov/wp-content/uploads/Data_Sharing_Policy_Proposed_Provisions.pdf