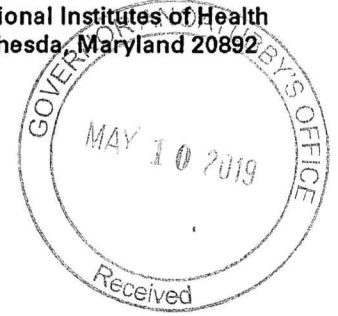




DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
Bethesda, Maryland 20892



April 17, 2019

Dear Tribal Leader and Urban Indian Organization Leader:

I am writing to initiate a Tribal Consultation and an Urban Confer on provisions for the National Institutes of Health (NIH) draft policy on Data Sharing and Management for NIH Funded or Supported Research. We are seeking your input on key elements of how this policy should be drafted to support meaningful participation of Tribes in biomedical research. More specifically, how do Tribes define Scientific Data and what are the requirements for acceptable Data Sharing and Management Plans for proposed research with Tribal communities?

The NIH mission, achieved through research, research training, and the dissemination of research findings, is to seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, lengthen life, and reduce illness and disability. 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.

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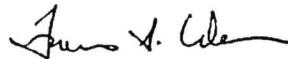
In accordance with the U.S. Department of Health and Human Services (HHS) Tribal Consultation Policy, NIH is announcing a ***Tribal Consultation on Data Sharing and Management for NIH Funded or Supported Research***. We encourage you to participate in these important events, which will convene in multiple regions: June 18-20 in Sacramento, CA; July 15-18 in Washington, DC; and August 20-22 in Denver, CO. For additional information, please visit the HHS Office of Intergovernmental and External Affairs website, available at the following link: <https://www.hhs.gov/about/agencies/iea/tribal-affairs/consultation/index.html>

If you are unable to travel for the consultation meeting, we will have a toll-free conference line available. Additionally, you are encouraged to send any testimony, comments, and questions before and after the consultation meeting to: NIHTribalCommittee@od.nih.gov.

The NIH remains committed to continuing its efforts to maintain and improve relations with Tribal nations, and to partnering with Tribal nations to use the power of science 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.

We look forward to receiving your input as we work to improve the health of American Indian and Alaska Native communities through research.

Sincerely yours,

A handwritten signature in black ink, appearing to read "Francis S. Collins".

Francis S. Collins, M.D., Ph.D.
Director