

August 28, 2014

NIH Releases Final Genomic Data Sharing Policy

Policy to Take Effect January 25, 2015

Earlier today, the U.S. National Institutes of Health (NIH) released its new Genomic Data Sharing (GDS) Policy, which applies to all NIH-supported research that generates large-scale, human or non-human genomic data and the use of this data for future research. The policy requires researchers seeking and receiving NIH funding to:

- Work with Program Officers to develop a Genomic Data Sharing Plan as part of their funding applications and review these plans throughout the grant cycle
- Share non-human genomic data and relevant associated data in a timely fashion, through any widely-used data repository
- De-identify and share human genomic data and relevant associated data in a timely fashion, through any NIH-designated data repository
- Register all studies with human genomic data in dbGaP
- Determine to what extent human genomic data should be shared with other researchers, keeping in mind informed consent agreements and limitations on how data is used
- Access, use, and acknowledge genomic data from others in accordance with guidelines

The final policy, which incorporates feedback from stakeholders and the public, was published in the *Federal Register*. As research progresses and new questions and issues arise, NIH will periodically review the policy and modify it as necessary, keeping investigators and institutions apprised of any changes.

Reference

Federal Register. (Aug. 28, 2014). Final NIH Genomic Data Sharing Policy. Doc. No. 2014-20385. Online at <https://federalregister.gov/a/2014-20385>.