



NIH Issues Final Genomic Data Sharing Policy

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The National Institutes of Health (NIH) recently issued its final NIH Genomic Data Sharing (GDS) policy designed to promote data sharing as a way to accelerate the translation of data into knowledge, products, and procedures that improve health but also protect the privacy of research participants.

Beginning in January 2015, the policy will apply to all NIH-funded, large-scale human and non-human projects that generate genomic data. The GDS policy replaces the Genome-Wide Association Studies (GWAS) data sharing policy. According to the NIH, "A key tenet of the GDS policy is the expectation that researchers obtain informed consent of study participants for the potential future use of their de-identified data for research and for broad sharing."

The expectation is that investigators and their institutions will provide basic plans for following the GDS policy as part of funding proposals and applications. The agency is taking steps to evaluate and monitor the impact of data sharing costs on the conduct of research, programmatically through the Big Data to Knowledge (BD2K) Initiative, and organizationally through the creation of the Scientific Data Council. The Council will advise the NIH on issues related to data science.

NIH established the BD2K initiative, designed to accelerate the pace of discovery through the use of biomedical Big Data, in 2012 (see Update, [November 12, 2013](#)). The goal of BD2K is to enable a quantum leap in the ability of the biomedical research enterprise to maximize the value of the growing volume and complexity of biomedical data by the end of this decade. It is led by [Philip Bourne](#), NIH's new Associate Director for Data Science.

Additional information regarding the new GDS policy is available in the [NIH Guides Grants and Contracts](#) or the [Federal Register](#).