

Responding to Data Management and Sharing Requirements in the Health Sciences

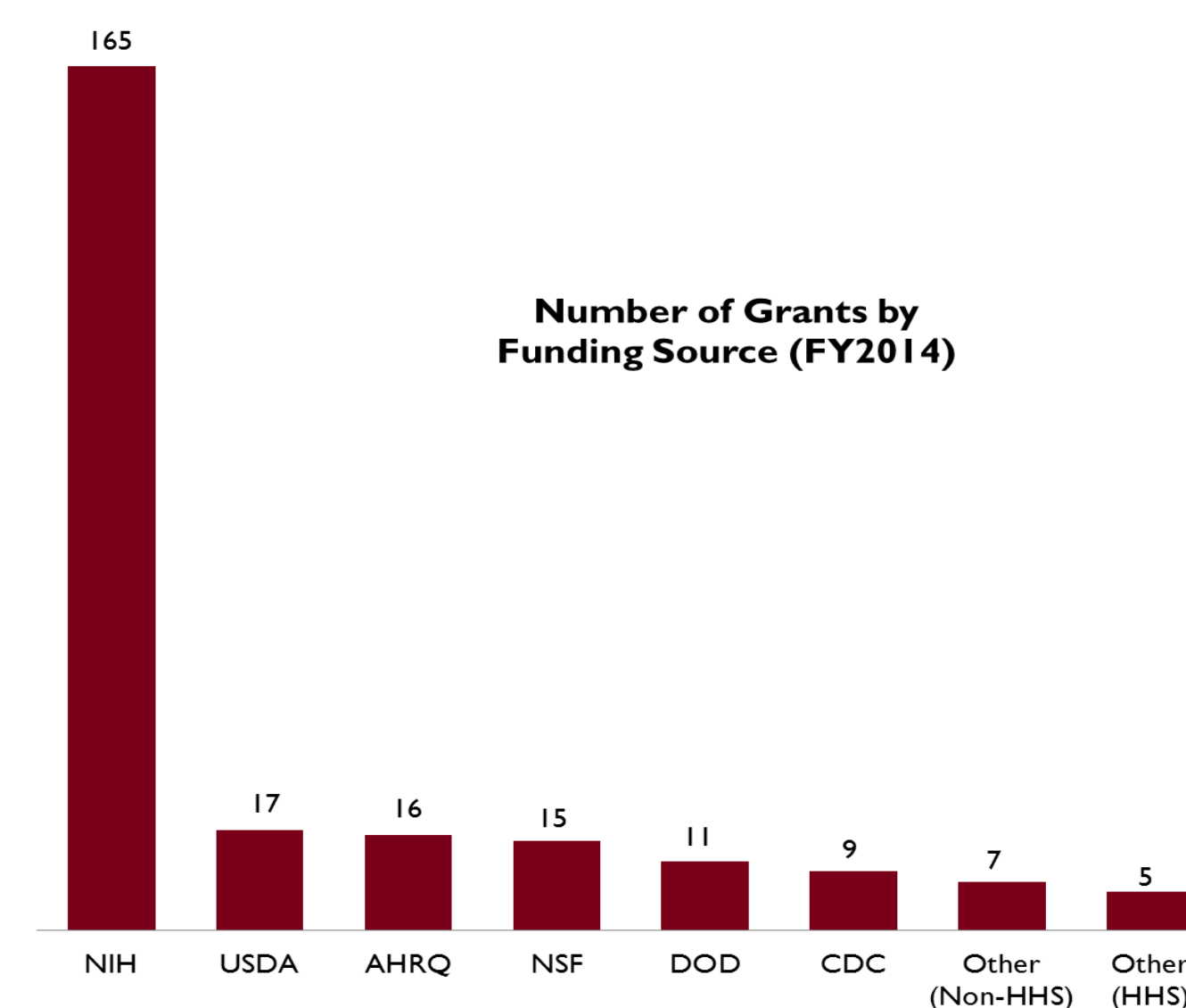
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Background

The University of Minnesota's Academic Health Center (AHC) is comprised of six colleges and schools with a total of 46 departments, and includes approximately 1,500 full time faculty, 6,000 professionals and graduate students, and over 3,000 adjuncts.

The majority of the AHC's federal research funding is issued by NIH. The remaining 1/3 of grants come from a diverse mix of agencies (1).



A Whole New World

In FY2014, approximately 11% of federally funded research in the AHC was subject to data management or data sharing requirements (1-3). Following implementation of the OSTP responses, an estimated 85% would have these requirements. For many researchers in the health sciences, DMPs are a foreign concept. In a 2014 survey of AHC researchers, 72% indicated that they had never written a data management plan (4).

Potential Challenges

Application Fatigue: Preparing grant applications has been called "the most arduous task" in a researcher's career (5). In an increasingly competitive funding environment with changing requirements for a variety of elements, such as the NIH biosketch, the prospect of writing a DMP could potentially be viewed unfavorably.

HIPAA/PHI: Researchers, while aware of HIPAA and PHI, are not trained to de-identify datasets for public consumption and are rightfully concerned about potentially comprising participant privacy. Furthermore, established IRB processes and informed consent documents may be restrictive.

Diversity of Data: Health sciences researchers interact with almost every type of data, from genomics data to electronic health records to long-form surveys, and often producing multiple types of data. In the 2014 survey, 43% of respondents reported creating five or more types of data in their research (4).

Summarizing Plans

Of the 14 federal agencies that most frequently fund AHC research, 12 are subject to the OSTP memo and 10 have released plans including data requirements. While established best practices and Health and Human Services's common approach have led to some consistency, there are notable differences.

What's in a DMP?



Requirements span a broad range, from minimal guidance in the USAID and USDA plans to an extensive template from CDC. Beyond the standard elements, researchers may also be asked to describe other aspects of their data management strategies, including processes for removing sensitive information and how long the data will be preserved and accessible.

Where do the data go?



The majority of funders are encouraging the use of existing publicly available repositories. However, a relatively large minority of those funders are also requiring the use of a data registry to compile metadata and serve as an access point. There is little overlap between agencies regarding the named repositories or registries, whether required or suggested.

When do they have to be there?



In the majority of cases, data are to be made available concurrently with article publication or within a specified time period, most typically within 12 months. However, in some cases these timelines are tentative or exploratory and may be revisited as plans are implemented and mature.

Approaches

Connecting to the Public Access Policy: Researchers in the AHC are very familiar with the policy and the University of Minnesota's overall compliance rate is 90%. Framing data management and sharing requirements as an extension of a familiar process grounds the conversation.

Targeting Research Support Staff: Grants coordinators, research facilitators, and administrative assistants are often the first line for researcher questions. At the University of Minnesota's 2016 Sponsored Projects Symposium, our presentation on data management requirements drew approximately 14% of grants coordinators at the University of Minnesota, indicating that there is a need for this outreach.

Refining, Not Reinventing: The University of Minnesota Libraries has a robust and well-established suite of data management services, including a data repository. Existing materials and expertise can be easily connected to emerging requirements, providing seemingly ready-made solutions for researchers. Tailoring to acknowledge and address potential challenges for health sciences researchers—like de-identification—makes these services more relevant.

Next Steps

The Libraries' data management web page provide current information for researchers on these emerging plans and the Libraries' existing data management and sharing services. Ways in which this information can be enhanced are being explored. We are continuing to work with our Sponsored Projects Administration to connect with grant coordinators and research support staff, while outreach opportunities are pursued throughout the AHC in collaboration with liaison librarians. Effectively meeting these needs will require a sustained effort which is personalized to meet the unique needs of research groups as these plans are fully implemented.

References

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