NIH DMS plans

Selecting a Data Repository

For data generated from research for which no data repository is specified by NIH, researchers are encouraged to select a data repository that is appropriate for the data generated from the research project. Be sure to consult the list of <u>desirable characteristics</u> and the following guidance:

- Primary consideration should be given to data repositories that are discipline or data-type specific to support
 effective data discovery and reuse. For a list of NIH-supported repositories, visit Repositories for Sharing Scientific
 Data.
- If no appropriate discipline or data-type specific repository is available, researchers should consider a variety of other potentially suitable data sharing options:
 - o Small datasets (up to 2 GB in size) may be included as supplementary material to accompany articles submitted to PubMed Central (<u>instructions</u>).
 - o Data repositories, including <u>generalist repositories</u> or institutional repositories, that make data available to the larger research community, institutions, or the broader public.
 - o Large datasets may benefit from cloud-based data repositories for data access, preservation, and sharing.

Repositories for Sharing Data

Overall, NIH encourages researchers to select the repository that is most appropriate for their data type and discipline. Certain Institutes have designated repositories (i.e., NIMH, NIDDK)

The repositories list is searchable by NIH Institute/Center and research domain (e.g., genetic data, behavioral data [https://ldbase.org/, https://nda.nih.gov/], imaging data [https://openneuro.org/]). Many of these repositories have sample templates for data management plans available for use (e.g., https://ldbase.org/resources/templates).

Each repository also has documentation and descriptions to help guide researchers, as well as FAQs (i.e., https://ldbase.org/resources/first-time-storing-data) and cost estimation resources (i.e., https://nda.nih.gov/nda/data-contribution.html#cost).

Budgeting for Data Management & Sharing

Investigators may request funds toward data management and sharing in the budget and budget justification sections of their applications. Costs must be incurred *during* the project period.

The National Academies of Science, Engineering, and Medicine has developed a resource <u>"Forecasting Costs for Preserving, Archiving, and Promoting Access to Biomedical Data"</u> that may be useful when budgeting for data management and sharing costs.

Data Management & Sharing FAQs

Including definitions of scientific data, timing of data sharing, issues related to informed consent, etc.

<u>Data Sharing Tiers (from JHURA)</u> --reviews requirements and considerations for openness of sharing, level of identifiability of data/associated risks, explicitness of consent, requirements for Data Trust review:

Public/open sharing (no data use agreement), mediated sharing (DUA required, no human review), mediated sharing with human review (DUA, human review required), enclave data sharing (download prohibited)

Additional Guidance & Resources for navigating Data Sharing requirements:

Sheridan Libraries Data Management & Sharing Writing a Data Management & Sharing Plan

The https://dmptool.org/ and DMP Tool funder regs
The JH Data Trust has webinars/brown bag sessions listed/archived here: https://jhura.jhu.edu/brownbag-2/

Kirby Center Imaging data

Kirby largely relies on sharing via https://www.nitrc.org/ Kirby has a process for de-identifying and defacing/refacing MRI imaging: https://godzilla.kennedykrieger.org/dicomfiles/dicomanon.html (credit: J Gillen)