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The NIH Data Management and Sharing Policy, effective on January 25, 2023, requires the submission of a Data Management and Sharing Plan with each proposal for research that will generate scientific data. The Policy permits investigators to request funds to support the data sharing and management activities proposed in the plan submitted. (See NOT-OD-21-015: Allowable Costs for Data Management and Sharing).

What can be charged?

Reasonable, allowable costs associated with DMS plans should be requested in the budget and budget justification sections of the application. Cost that can be direct charged to the award include costs for:

- Curating data

- Developing supporting documentation

- Formatting data according to accepted community standards, or for transmission to and storage at a selected repository for long-term preservation and access

- De-identifying data

- Preparing metadata to foster discoverability, interpretation, and reuse

- Local data management considerations, such as unique and specialized information infrastructure necessary to provide local management and preservation (for example, before deposit into an established repository).

- Preserving and sharing data through established repositories, such as data deposit fees.

  o If the Data Management & Sharing (DMS) plan proposes deposition to multiple repositories, costs associated with each proposed repository may be included.

Budget requests must NOT include:

- o Infrastructure costs that are included in institutional overhead (for instance, Facilities and Administrative costs)

- o Costs associated with the routine conduct of research, including costs associated with collecting or gaining access to research data.

- o Costs that are double charged or inconsistently charged as both direct and indirect costs

Budget requests should be included in one of the following ways:

1. Using the R & R detailed budget form in a line item labeled "Data Management and Sharing Costs" under Other Direct Costs along with the Budget Justification attachment.

2. Using the *PHS 398 Modular Budget Form:* Use the Additional Narrative Justification attachment of the PHS 398 Modular Budget Form

All DMS costs- including personnel costs- should be included in the Data Management and Sharing Costs line item.

Justifications should be labeled as "Data Management and Sharing Justification" and be no more than half a page.

How much dedicated staff time will be required to support the data management and sharing activities proposed in the DMS plan? (See BEAD Core Best Practice for guidance)

Will staff or a service center/third party vendor be performing any of the following activities:

- Curating data

- Developing supporting documentation

- Formatting data according to accepted community standards, or for transmission to and storage at a selected repository for long-term preservation and access

- De-identifying data

- Preparing metadata to foster discoverability, interpretation, and reuse

If service center/third party vendor is performing any of the above activities, include those costs in the DMS budget.

Are there data storage/repository costs applicable?

Are there costs/fees associated with any specialized information infrastructure necessary to provide local management and preservation of the data (e.g., PMAP)?

Are any subrecipients performing any of the DMS activities?

NOTE: All costs submitted in budget requests must be incurred during the period of performance of the award- even if data sharing and storage will extend beyond termination of the award.   For example, if the DMS plan proposed sharing of data for 10 years in a repository with an associated cost, the cost for the entire 10 years must be paid before the expiration of the grant. Therefore DMS expenses may need to be prepaid prior to expiration/close out of the award.

JHU Data Management and Sharing Resources:

Biostatistics, Epidemiology and Data Management (BEAD) Core

The BEAD Core provides research support services to subscribing department investigators, and as a direct fee for service for other investigators. BEAD Core also provides assistance with grant submissions, writing data management and statistical analytic plans as well as assisting with the study design and research aims.

BEAD Core Budgeting Best Practices for Data Management and Sharing include suggested costs for routine data management and sharing:

1. R01-level funding:
   a. 40% of a data manager per year ($30K to $40K);
   b. 2-5% Co-I to supervise/guide data manager (range $5-10K)
2. R21-level funding:
   a. 20% of a data manager per year ($15K to $20K)
   b. 2% Co-I to supervise/guide data manager (range $5K)
3. U's (such as a U54) (typically three RO1s combined)
   a. 100% of a data manager (some efficiency gained, but depends on the three projects included)
   b. 10% of a Co-I
4. K-level funding:
   a. 20-40 hours per year ($120/hr)

Costs may be replaced with BEAD Core subscription hours either in full or in part for faculty in subscribing departments.

Costs are provided as suggestions only. Costing should be commensurate with the activities of the individual DMS plan.

Core for Clinical Research Data Acquisition

The Core for Clinical Research Data Acquisition (CCDA) is one of the 10 **Data Trust** analytic teams responsible for assisting researchers with accessing clinical data for research. CCDA provides the following services:

1. Preliminary, anonymous data for feasibility, grant applications and statistical population sample-size estimates

2. IRB-approved case-finding for study enrollment (mailings, phone solicitation), chart review, and cohort/case-control studies

3. Natural Language Processing service–Text mining and information extraction methods to identify disease, medications, symptoms, and signs from clinical text, as well as artificial intelligence techniques for sentiment analysis, opinion mining, measuring cognitive ability, and exploring social determinants of health.

4. Research data extracts

5. Data de-identification services to confirm to **HIPAA Privacy standards**

6. Honest Broker services

7. Assistance using Epic's SlicerDicer and TriNetX self-service tools

Johns Hopkins Precision Medicine Analytics Platform (PMAP)

The PMAP platform pulls data from the Epic Medical Record and other data sources into a Data Commons, where the data are integrated together and available in a format that is operable by sophisticated machine learning and natural language processing technologies. PMAP also offers secure storage and data management environment with many analytical tools included the PMAP pricing structure.

JHU Data Archive

JHU Data Archive is an open access repository for the long-term management and preservation of research data. Through depositing datasets in the JHU Data Archive, researchers are able to share their research data with the public for future discovery and reuse. The JHU Data Archive

is administered by professional curators, who will work with you to ensure your data is Findable, Accessible, Interoperable and Reusable ([FAIR](#)).

JHU Data archive is free for up to 1TB for users who are affiliated with JHU divisions that participate in our funding model. You can find the list of participating divisions [here](#). Fees may apply above 1TB.

Note- not all data is appropriate for sharing in an open access repository. [The NIH DMS policy encourages researchers and institutions to consider whether human subjects data- even de-identified-should be shared via controlled access.](#)

==**External DMS budgeting/cost resources:**==

[NDA Data Submission Cost Estimation Tool](#)   NIMH has a cost estimation tool used for costs associated with submitting data to the NIMH Archive (NDA).

The National Academies of Science, Engineering, and Medicine resource ["Forecasting Costs for Preserving, Archiving, and Promoting Access to Biomedical Data"](#)

==**Other Data Management and Sharing Resources:**==

NOT-OD-21-013: [Final NIH Policy for Data Management and Sharing](#)

NOT-OD-21-014: [Supplemental Information on Elements of an NIH Data Management and Sharing Plan](#)

NOT-OD-21-015: [Allowable Costs for Data Management and Sharing](#)

NOT-OD-22-213: [Supplemental Information to the NIH Policy for Data Management and Sharing: Protecting Privacy When Sharing Human Research Participant Data](#)

[NIH Data Management and Sharing Policy website](#)

[Sample DMS Plans](#) – to be used for educational purposes not as templates.

[Repositories for Sharing Scientific Data](#)

[NIH Guidance on Budgeting for Data Management and Sharing](#)

[DMPTool](#)