# NIH Scientific Data Sharing

What you need to know and resources to help with implementation

# NIH Data Management & Sharing Plan (DMSP) Policies

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# What are the new NIH DMSP policies? Why are they important?

Purpose: to promote the management and sharing of scientific data generated from NIHfunded or conducted research. Clarifying Expectations for Sharing ScientifiData

does not create a uniform requirement to share all scientific data

the requirement to submit a Plan researchers are prospectively planning for data sharing integrate data sharing into the routine conduct of research

requirement for submission of Plans

Through

increasingly lead researchers to

# What are the new NIH DSMP policies? Why are they important?

Assessment of Plans

The final DMS Policy maintains NIH Program Staff assessments of Plans' merits. management and sharing, although these comments will not impact the overall score.

NIH Institutes, Centers and Offices (ICO) Consistency of Data Sharifig pectations

peer reviewers may comment on the proposed budget for data

we intend to promote

When Data Are Expected To Behared

"[s]hared scientific data should be made accessible as 1gH2 11 rererssible a, () 20-1(a)-2 (cc) 15.3-1 () 301(a)ss 4 (e)-2 (t)-1 (a)1 (ar2 () 20 (sht1 (h)2 (a)-2 (r)) 15.3 t1 (h)2 (a

Page Limit and Template forPlans

we have noted the elements to be addressed in two pages or less, indicating that these descriptions need not be long

narratives.

The Acceptability of To Be Determined" as a Response to Plan Elements

Information eliminates the language that a response of "to be determined" is acceptable

Timelines for Using Funds for Data Management and Sharing Activities

Personnel costs required to perform the types of data management and sharing activities described in the final Supplemental I nfo rmation are allowable.

• Applies to all research, funded in whole or in part by NIH, that results in the generation of "scientific data"

• "Scientific data" is defined as: "the recorded factual material commonly accepted in the scientific community as of sufficient quality to validate and replicate research findings, regardless of whether the data are used to support scholarly publications."

• Does not apply to funding that does not generate data

### Exclusions from the DMSP

Scientific data not included:

- Data not necessary for or of sufficient quality to validate and replicate research findings,
- Laboratory notebooks
- Preliminary analyses
- Completed case report forms
- Drafts of scientific papers
- Plans for future research
- Peer reviews
- Communications with colleagues
- Physical objects (e.g., laboratory specimens)

# Elements of a DMS Plan

|               | Data Type                                | Identify data and metadata to be preserved and shared   |
|---------------|--|---|
| Plan Elements | Tools, Software, Code                    | Tools and software needed to access and manipulate data                                       |
|               | Standards                                | Standards to be applied to scientific data and metadata                                       |
|               | Data Preservation,<br>Sharing, Timelines | Repository to be used, persistent unique identifier, and when/how long data will be available |
|               | Access, Distribution,<br>Reuse           | Description of factors for data access, distribution, or reuse                                |
|               | Oversight                                | Plan compliance will be monitored/managed and by whom   |

# Elements of a DMS plan: Data preservation, sharing, timelines

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### NIH Data Sharing Landscape

NIH encourages the use of established data repositories

Improves the FAIRness of Data (Findable, Accessible, Interoperable, Reusable)

sensitivity of data size of dataset complexity of data

#### Desirable Characteristics for All Data Repositories

- <sup>3</sup>⁄<sub>4</sub> Unique Persistent Identifiers
  <sup>3</sup>⁄<sub>4</sub> Long-Term Sustainability
  <sup>3</sup>⁄<sub>4</sub> Metadata
  <sup>3</sup>⁄<sub>4</sub> Curation and Quality Assurance
- <sup>3</sup>⁄<sub>4</sub> Curation and Quality Assurance
- <sup>3</sup>⁄<sub>4</sub> Free and Easy Access
- <sup>3</sup>⁄<sub>4</sub> Broad and Measured Reuse

- <sup>3</sup>⁄<sub>4</sub> Clear Use Guidance
- <sup>3</sup>⁄<sub>4</sub> Security and Integrity
- 3/4 Confidentiality
- 3/4 Common Format
- <sup>3</sup>⁄<sub>4</sub> Provenance
- <sup>3</sup>⁄<sub>4</sub> Retention Policy

| 3/4 Clear Use Guidance   | 3/4 Restricted Use Compliant | 3/4 Download Control |
|--------------------------|------------------------------|----------------------|
| 3/4 Retention Guidelines | 3/4 Privacy                  | 3/4 Violations       |
| 3/4 Fidelity to Consent  | 3/4 Plan for Breach          | 3/4 Request Review   |

# Finding and selecting a repository

- NIH Supported subject-specific, open-access repositories
- Primary consideration should be given to data repositories that are discipline or data-type-specific



- BioSystics Analytics Platform (BioSystics-AP)
- National COVID Cohort Collaborative (N3C)
- Natural Products Magnetic Resonance Database (NP-MRD)
- ETC.....

# Tools and resources to help

# USA Institutional Repository

JagWorks@USA Repository

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Wide range of content and materials

Examples: (not an exhaustive list) Theses/Dissertations Conference presentations/posters Journal articles Journals published at USA Datasets Images Accreditation documentation Open educational resources Podcasts Tex

#### Limitations on data sharing

Justifiable ethical, legal, and technical factors:

- Informed consent will not permit or limits scope of sharing or use
- Privacy or safety of research participants would be compromised and available protections insufficient
- Explicit federal, state, local, or Tribal law, regulation, or policy prohibits disclosure
- Restrictions imposed by existing or anticipated agreements with other parties

Reasons **NOT** acceptable to limit sharing:

- Data are considered too small
- Data will not be widely used
- Data are not thought to have a suitable repository

For more information and questions?