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[https://www.library.rochester.edu/services/
data-management-and-sharing](https://www.library.rochester.edu/services/data-management-and-sharing)

Mastering Your NIH Data Management and Sharing Plan



Data Services Team

We can:

- Answer any questions you have via email or 1-on-1 consultations
- Review your data management and sharing plan or your dataset
- Help you choose a repository
- Help you prepare your data to be shared
- Help you use URRR
- Help you use other data software and tools
- Offer private training to your research group

Visit our webpage to learn more about our services and our contact information: <https://www.library.rochester.edu/services/data-management-and-sharing>

Agenda

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NIH Data Management & Sharing Policy

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Data Management and Sharing Service,
Resources & Tools

3

Q & A

NIH Data Management & Sharing Policy





DMS Policy

The NIH Data Management and Sharing (DMS) Policy is a set of requirements and guidelines related to the management and sharing of research data generated by work funded wholly or partially by the National Institutes of Health (NIH). This policy applies to all proposals received after January 25th, 2023, that result in the generation of scientific data.

DMSP

A Data Management and Sharing Plan (DMSP) is a document included in applicable NIH proposals that prospectively outlines how a research team intends to manage, preserve, and share the scientific data associated with the proposed work.

In Summary...

Researchers applying for NIH funding need to:

- Write a DMSP as part of their grant application
- Comply with it (therefore, share their scientific data)

What is Scientific Data?

It includes...

- Any data 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
- Any data needed to validate and replicate research findings

It does not include...

- Laboratory notebooks
- Preliminary analyses
- Compared case report forms
- Drafts of scientific papers
- Plans for future research
- Peer reviews
- Communications with colleagues
- Physical objects such as laboratory specimens.

[NIH. \(n.d.\). Research covered under the data management & sharing policy.](#)



Justifiable Reasons for Limiting Sharing of Data

It is understood that some data cannot be shared openly or even at all, due to certain ethical, legal, and social issues.

Reasons include...

- Informed consent will not permit or will limit the scope or extent of sharing and future research use
- Existing consent prohibits sharing or limits the scope or extent of sharing and future research use
- Privacy or safety of research participants would be compromised and protective measures such as de-identification and Certificates of Confidentiality would be insufficient.
- Explicit federal, state, local, or Tribal law, regulation, or policy prohibits disclosure
- Restrictions imposed by existing or anticipated agreements
- Datasets cannot practically be digitized with reasonable efforts



However, you MUST include a rationale for why scientific data will not be shared.

When Does it Need to be Shared?

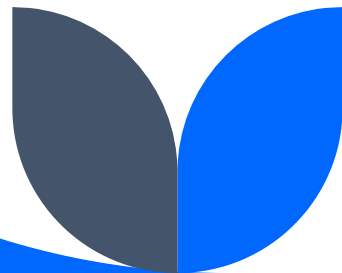
According to the DMS Policy, scientific data needs to be shared by the earlier of two timepoints:

The time of an associated publication

OR

The end of the performance period (unless the grant enters into a no-cost extension).

In the case of a no-cost extension, data management and sharing-related requirements are extended to the end of the extended performance period.



General Advice from the NIH

- Two pages is just a recommendation – it **can be longer**.
- Don't be afraid to **use tables** – it is easier for the NIH to read.
- Be careful **not to contradict** yourself.
- Some individuals mention planning to share only through “publications” and “conferences” or “by request.” This is **not enough!**
- **Check out the examples** on the [NIH Website](#).



Reoccurring Issues Noted by the NIH

Sharing

- Vague reasons are given for not sharing
- Sharing methods are too restrictive without a justifiable reason why

Budget

- Budget does not include DMS activities

Repository

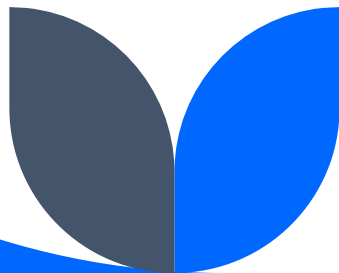
- No repository is chosen
- An ill-fitting repository is chosen
- When using multiple repositories, not specifying which data goes to which repository
- Overreliance on generalist repositories (make sure a subject-specific one doesn't exist!)

Data

- Not clear on which data will be generated and which data will be shared
- Lack of detailed description about data types (including estimated amounts).

Standards

- Researchers are being vague or not mentioning any standards at all.
- Check out NIH CDE repository, NCI-thesaurus, NNLM, and CaDSR.



DMSPs for NIH Require 6 Elements



Data Types



Related Tools, Software and/or Code



Data Standards



Data Preservation, Access, and Associated Timelines



Data Sharing Agreements, Licenses, and Other Use Limitations



Oversight of Data Management

[NIH. \(2020\). Supplemental information to the NIH policy for data management and sharing: Elements of an NIH data management and sharing plan.](#)

Data Type - Summary

- Summary of the types and estimated amount of scientific data.
- Descriptions may include data modality, level of aggregation, and degree of data processing.
- Description of which scientific data from the project will be preserved and shared. Remember, NIH does not anticipate for all scientific data to be shared. You must provide a rationale for these decisions.
- A brief listing of the metadata, other relevant data, and any associated documentation that will be made accessible to ensure the scientific data is understandable and interpretable.



[NIH. \(2020\). Supplemental information to the NIH policy for data management and sharing: Elements of an NIH data management and sharing plan.](#)

Data Type - Example

This project will produce **imaging** data generated/obtained from **ultrasonography**. Data will be collected from **10** of research participants/specimens/experiments, generating **1** datasets totaling approximately **half a GB** [amount of data] in size. The following data files will be used or produced in the course of the project: **DICOM**. Raw data will be transformed by **filtering and enhancing the images** and the subsequent processed dataset used for statistical analysis. To protect research participant identities, **individual** data will be made available for sharing.



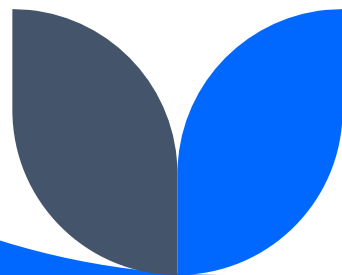
[Adapted from NIH. \(2022\). 2023 NIH Data Management and Sharing Policy.](#)

Data Type – Table Example

Element 1: Data Type

A. Types and amount of scientific data expected to be generated in the project:

Type	Species	Platform/ Source	Amount
Array-derived genotype data	Human	Illumina	1,000 research participants (500 cases/controls), prospective enrollment
30x whole-genome sequence data	"	"	"
RNA-seq data	"	"	"
Hi-C WGS	"	"	"
Phenotypic and clinical data	"	Institutional EHR	"
Demographic data	"	"	"



Data Type – What We've Noticed

- Researchers are forgetting to mention the file type
- Researchers are not including the amount of data (an estimate or range is ok).
- Researchers are mentioning the data they are sharing, but not being specific about the data they are not sharing (and why).
- Researchers are not including readmes and/or data dictionaries and/or methodology in the type of documentation they are sharing.



Related Tools, Software and/or Code

– Summary & Example

- List the names of **tool(s) and software** needed to access or manipulate shared scientific data to support replication or reuse.
- If necessary, specify **how these tools can be accessed**, and if the tools are likely to remain available.

Imaging data will be made available in **DICOM** format, which requires the use of **MicroDicom** to be accessed and manipulated. The **MicroDicom** tool, which can be used to **view the images** is available free of charge through <https://www.microdicom.com/>.

[NIH. \(2020\). Supplemental information to the NIH policy for data management and sharing: Elements of an NIH data management and sharing plan.](#)

[Adapted from NIH. \(2022\). 2023 NIH Data Management and Sharing Policy.](#)



Related Tools, Software and/or Code

– What We've Noticed

- Researchers are not specifying the version of the software or tools they are using.
- Researchers are not specifying whether these tools are open or proprietary. They are not specifying how they can be accessed.
- Individuals are not giving URLs to the tools. [Note: Do not hypertext links.]



Standards - Summary

- Indication of what **standards** will be applied to the scientific data and associated metadata:
 - Data formats
 - Data dictionaries
 - Data identifiers
 - Definitions
 - Unique Identifiers
 - Other data documentation
- Plan may indicate that **no consensus** data standards exist for the scientific data and metadata



[NIH. \(2020\). Supplemental information to the NIH policy for data management and sharing: Elements of an NIH data management and sharing plan.](#)

Standards - Examples

To facilitate their efficient use, all of our data and materials will be structured and described using the following standards: **Network Common Data Format**.

Alternatively

Formal standards for **DICOM** data have not yet been widely adopted. However, our data and other materials will be structured and described according to best practices.



[Adapted from NIH. \(2022\). 2023 NIH Data Management and Sharing Policy.](#)

Standards – Table Example

Element 3: Standards:

Data Type	Standard
Human array-derived genotype data	VCF
30x whole-genome sequence data	Sequencing data and variant calls will be shared in CRAM and VCF formats, respectively.
RNA-seq data	Data will be QCd and analyzed according to ENCODE Bulk RNA-seq Data Standards. FASTQs, BAM alignment files, and TSV transcript quantifications will be shared.
Hi-C WGS	FASTQ
Demographic, Phenotypic and Clinical Data	<ul style="list-style-type: none">• PhenX for surveys• RxNorm for meds• PCORnet CDM which is derived from OMOP for EHR data collection for secondary outcomes• Current Procedural Terminology (CPTs), Logical Observation Identifier Names and Codes (LOINCs) and diagnoses ICD10 codes
Study protocols	Customized (non-standard) & to be developed



[NIH. \(2022\). Sample DMS plan – Human genomic data project.](#)

Standards – What We've Noticed

- Researchers are being ambiguous here.
- Reach out to colleagues in your department or contact your subject librarian or other people with subject expertise.
- Look into research being done in your field. What standards are they using?
- If you are using a subject-specific repository, what standards do they use or recommend?
- NIH recommends these resources to learn more about different standards that exist: NIH CDE repository, NCI-thesaurus, NNLM, and CaDSR.
- You can search for standards on [FAIRsharing.org](https://fairsharing.org).



Data Preservation, Access, and Associated Timelines - Summary

- Name of repository(ies) where data will be archived and shared
- How the scientific data will be findable and identifiable (i.e., persistent unique identifier)
- When the scientific data will be made available and for how long.
- Identify any differences in timelines for different subsets of scientific data to be shared.
- Scientific data should be shared as soon as possible, and no later than time of an associated publication or end of the performance period.



[NIH. \(2020\). Supplemental information to the NIH policy for data management and sharing: Elements of an NIH data management and sharing plan.](#)

Data Preservation, Access, and Associated Timelines - Example

All dataset(s) that can be shared will be deposited in **University of Rochester Research Repository (URRR)**, which is the University of Rochester's instance of Figshare.

Figshare provides metadata, **DOI** persistent identifiers, and long-term access. This repository is supported by **University of Rochester Librarians and Data Curators**, who check all data before it is shared to ensure data quality and **findability**, and dataset(s) are available under a **Creative Commons CC0 license**. The links to the datasets will be included in all **publications and in the ORCIDs** of all of the researchers.

Data will be made available as soon as possible or at the time of associated publication, whichever comes first.



[Adapted from NIH. \(2022\). 2023 NIH Data Management and Sharing Policy.](#)

Data Preservation, Access, and Associated Timelines – What We've Noticed

- Researchers do not name a specific repository
- Researchers do not specify that they will ensure their data has a persistent unique identifier (if you use Figshare, you will automatically receive a persistent unique identifier when you publish your data and can reserve it ahead of time).
- Researchers do not mention linking to their data in their publications and ORCID.



Where Should You Share Your Data?

1

Subject(Domain)-Specific Repositories

2

University of Rochester Research
Repository (URRR)

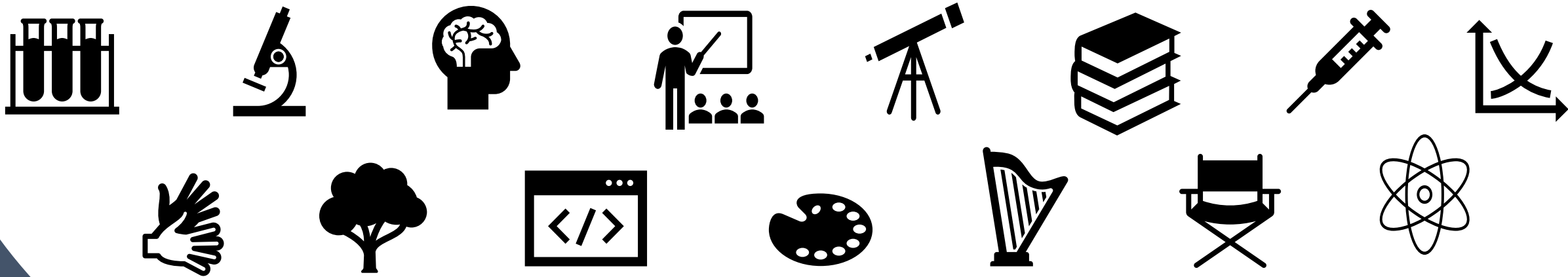
3

Other Generalist Repositories

What is a Subject-Specific Repository?

A Subject-Specific Repository (or a Domain-Specific Repository) is a repository which stores and shares data for a specific subject.

However, not all subjects have a subject-specific repository available.



How Can I Find a Subject-Specific Repository?

Where are other people in your field sharing their data?

Ask your colleagues, examine journal articles and other publications, and check funder recommendations.

Reach out to your Subject Librarian on the River Campus, at the Medical Center, or at Eastman for assistance.

NIH has a list of [subject-specific repositories](#) they recommend!

If there is no subject-specific repository...

Try the University of Rochester Research Repository
(URRR)





University of Rochester Research Repository (URRR)

Controlled access with embargo and private link

UR Instance of Figshare, a Generalist Repository

All UR members can deposit up to 10 GB of Data – contact us for more

Reserve a DOI ahead of time

Curation Service – we will check your data

Can share data, posters, articles, images, presentations, etc



Third Option: Generalist Repositories



- A generalist repository is not subject-specific and accepts all kinds of data.
- There are 7 main generalist repositories: Harvard Dataverse, Dryad, Figshare, Mendeley Data, OSF, Vivli, and Zenodo.
- These repositories are part of GREI, the generalist repository ecosystem initiative.

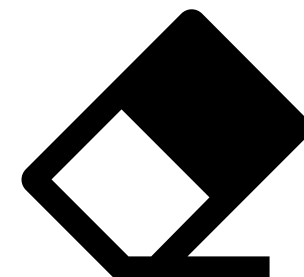
[Check out the Generalist Repository Comparison Chart to Compare the Repositories](#)

Sharing Restricted Access Data

If your data includes human participants, make sure you de-identify your data before you share it. De-identification requires you to remove any personal information from a dataset.

If de-identifying your data is not enough, you may be able to only share aggregated or summarized data. Or, you may want to share it in a repository which allows for restricted access.

[UR Data De-Identification Services](#)



ICPSR

a partner in social science research

Can share data
– free and pay
options (get
quote)

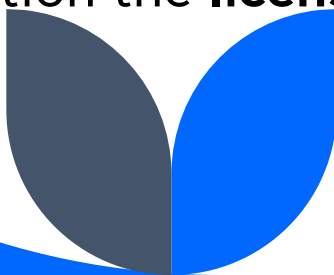
Focused on
social and
behavioral
research.

Can share
restricted access
data – ICPSR
staff handle
everything

Access, Distribution, or Reuse

Considerations - Summary

- Describe any **factors** affecting subsequent access, distribution or reuse of scientific data related to:
 - **Informed consent**
 - Privacy and confidentiality protections consistent with applicable federal, Tribal, state, and local **laws, regulations, and policies**
 - De-identification
 - Certificates of Confidentiality
 - Data Use Agreements
 - Other Protective Measures
 - Note whether **access** to scientific data derived from humans **will be controlled** (i.e., made available by a data repository only after approval).
 - Note any other **considerations** that may limit the extent of data sharing. You can mention the **license** you are putting your data under.



[NIH. \(2020\). Supplemental information to the NIH policy for data management and sharing: Elements of an NIH data management and sharing plan.](#)

Access, Distribution, or Reuse Considerations - Example

Tier	Data description	Data types
Public	Project protocols, and aggregated human subjects data	<ul style="list-style-type: none">•Interview protocols (.docx)•Analysis plans (.docx)•Aggregated survey data (.csv)•Aggregated codebook (.csv)
Restricted	Individual-level human subject data	<ul style="list-style-type: none">•De-identified survey responses (.csv)•Qualitative interview transcripts (.txt)•Interview codes (.csv)



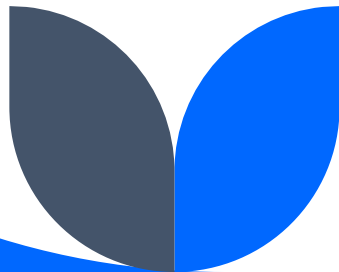
Access, Distribution, or Reuse Considerations – No Factors Example

There are no factors that will affect subsequent access, distribution or reuse of the scientific data. All data will be de-identified and we will not place any access controls over the data.



Access, Distribution, or Reuse Considerations – What We've Noticed

- Some people do not fully explain the restrictions they place on their data. This can include:
 - De-identifying your data (Protect human participants)
 - Aggregating your data (Protect human participants; sheer size of data)
 - Adding a license restricting how users can use the data.
 - Placing restrictions on who can look at the data
 - Establishing a Data Use and Transfer Agreement (DUTA)
- An example of possible language is the following:
 - "This research is focused on understanding the <insert scope of research>, any future use of the data must align with these research areas and not be used for any other purposes without obtaining additional informed consent from participants."



License

- CC0 1.0 Universal Public Domain Dedication
- CC BY 4.0
- CC BY-SA 4.0
- CC BY-NC 4.0
- CC BY-NC-SA 4.0
- CC BY-ND 4.0
- CC BY-NC-ND 4.0
- ODbL
- ODC-By
- PDDL
- MIT

Check out the [Creative Commons Website](https://creativecommons.org/) to learn more about CC Licenses.

Not all repositories will allow you to choose your own license!



Oversight of Data Management and Sharing - Summary

- Indicate how compliance in the Plan will be...
 - Monitored and managed
 - Frequency of oversight
 - By whom (e.g., titles, roles)



[NIH. \(2020\). Supplemental information to the NIH policy for data management and sharing: Elements of an NIH data management and sharing plan.](#)

Oversight of Data Management and Sharing - Example

Key Aspects to Consider:

- Who provides oversight?
- What are the various stakeholders' roles and responsibilities?

The PI on this project will be responsible for all aspects of data management and sharing, including collecting, analyzing, and describing the data, as well as uploading the data to **[INSERT REPOSITORY NAME]**. Compliance with the Plan will be monitored and managed, [include frequency of oversight], and by whom (e.g., titles, roles).



[Adapted from Samuel J. Wood Library. \(2022\). Oversight of Data Management and Sharing.](#)

Oversight of Data Management and Sharing – What We've Noticed

- Individuals are mentioning that compliance is being checked by the university – at the moment there is no plan in place for the university to be responsible for compliance.
- Individuals are not specifying who is responsible for what individual parts of data management and sharing.
- Individuals do not mention having a backup or security plan.
- **Important Note:** The University of Rochester will maintain all study records (i.e., regulatory files, data collection forms, source documentation) for at least 3 years after the research is completed, or for a longer term if required by other contractual agreements. If the consent form includes HIPAA Authorization, it must be maintained for 6 years.



Why Manage & Share Data?

Reproducibility

**Speed Up
Medical
Research**

**Managed
Data = Less
Mistakes**

**Publications
Linked to Data
Have Increased
Citation Counts**

Open Science

**Ensure Data is
Not Lost**

**Funded By the
Public**



Manage & Share Data Resources

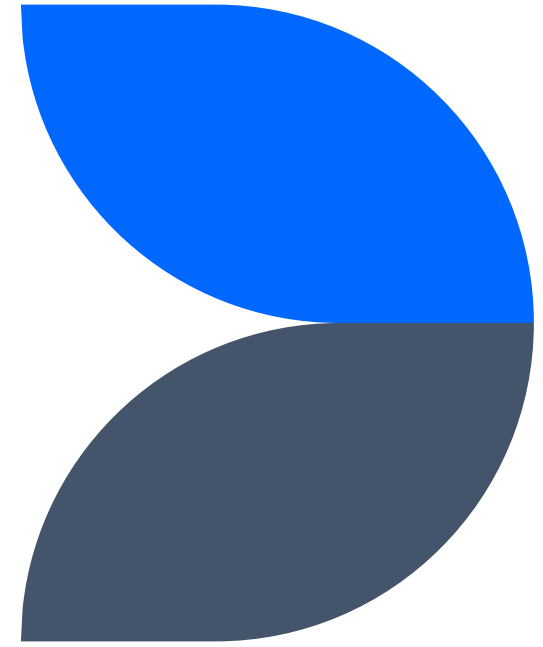
- Colavizza, G., Hrynaszkiwicz, I., Staden, I., Whitaker, K., & McGillibray, B. (2020). The citation advantage of linking publications to research data. *PLoS One*, 15(4). <https://doi.org/10.1371/journal.pone.0230416>
- Dattani, S. (2022, October 25). *The pandemic uncovered ways to speed up science*. WIRED. <https://www.wired.com/story/covid-19-open-science-public-health-data/>
- Kaiser, J., & Brainard. (2023, January 25). *Ready, set, share! As funders roll out new requirements for making data freely available, researchers weigh costs and benefits*. Science. <https://www.science.org/content/article/ready-set-share-researchers-brace-new-data-sharing-rules>
- Mullard, A. (2021, December 9). *Half of top cancer studies fail high-profile reproducibility effort*. Nature. <https://www.nature.com/articles/d41586-021-03691-0>



Q & A Break!



Data Services & Resources



Service Types

Answer Questions Via Chat or Email.

Offer one-on-one consultations in-person or via zoom.

Give private workshops/webinars to groups, classes, or dept. upon request

Review DMSPs for all Funders and Review Datasets

URL: <https://www.library.rochester.edu/services/data-management-and-sharing>



Areas of Specialization

DMSPs

Review plans and give advice for all funders

Reproducibility

Statistical methods, APIs, Scholarly Identity, ORCID, PIDs

Data Management Best Practices

Data and file management, documentation, readmes, data dictionaries, file naming conventions

Data Curation and Repositories

University of Rochester Research Repository (URRR), deposit and curate data, choose a repository

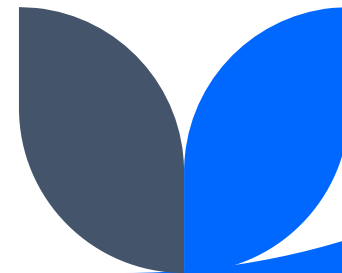
Data Visualization

Excel, Tableau, RStudio, Jupyter Notebooks, Python, Etc.

Data Tools

LabArchives, OSF, protocols.io, the DMPTool, ICPSR, and BioRender

URL: <https://www.library.rochester.edu/services/data-management-and-sharing>



Library Resources



NIH-Specific DMS Resource Guide – This guide offers detailed answers to common questions related to the NIH DMS Policy and has advice on how to create a DMSP for the NIH.



General DMS Resource Guide – This guide offers detailed advice on how to create DMSPs, and how to manage, organize, document, store, and share your data.



Templates – Templates using UR language.



We Want You To...

Submit Your Research!

URRR can store your datasets, posters, journal articles, creative works, and **more!**

Submitting to the **University of Rochester Research Repository (URRR)** can enhance your CV and includes:

- **DOIs!**
- **Usage metrics!**
- **10 GBs of storage!**
- **Long-term preservation!**
- **Listing in Google Scholar & Datasets!**
- **And so much more!**

WOW!



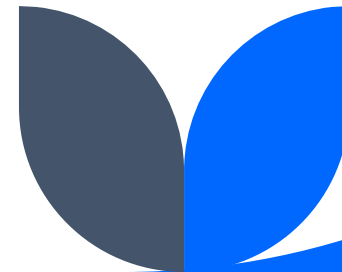
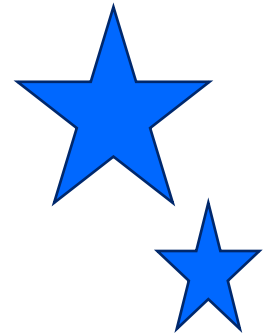
scan QR code



for more info



Reach Out to Us for Help
in Using URRR!
rochester.figshare.com



The logo for ICPSR (Inter-university Consortium for Political and Social Research) features the acronym in a large, blue, sans-serif font.Below the acronym is a horizontal bar with five colored squares (blue, orange, red, purple, green) followed by the text "a partner in social science research" in a smaller, blue, sans-serif font.

**You can deposit
here...**

**Focused on
social and
behavioral
research.**

**But UR
community
members also
have free access
to ICPSR data**



LabArchives

UR Community
Members Have
Free Access.

Use during the
research process to
keep your folders,
files, data, and
code, organized.

Optionally share
your notebook
publicly or with
guests. Optionally
publish it to get a
DOI.

An Electronic
Laboratory
Notebook (ELN).

Collaborate with
others and invite
people to your
journal. Has
version control.

Learn More on the [UR LabArchives Landing Page](#)



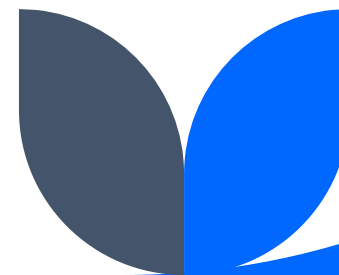
UR community members have
institutional access.

Can store files, data, code and other
materials. Every file gets a unique,
persistent URL, and it has version
control.

An open project management tool
that allows you to collaborate with
others on your research.

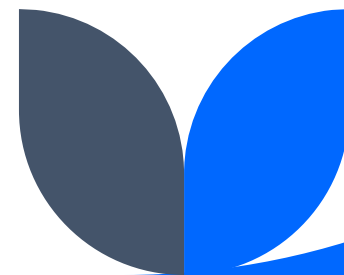
Can share all your research outputs.
Submit preregistrations and
registrations to the OSF Registry.
Share papers in OSF Preprints.

Travel to <https://osf.io/institutions/rochester>
Learn More: <https://libguides.lib.rochester.edu/osf>





- University of Rochester has **institutional access**. [Free]
- A **secure platform** where you can share methodology and protocols.
- **Version control** is built into the platform.
- Allows for **private & secure collaboration** with HIPAA compliance, audit trail, approval/signature, 2-factor authentication, encryption, VPC, and more.
- Can **share publicly, and link to** in your publications and your readme.
- Increases **reproducibility** of your research!



NIH Resources

- [Link to the Policy & Instructions on How to Write It](#)
- [That Constitutes as Research that Needs to Be Shared Under the NIH Policy](#)
- [Domain-Specific Data Repositories](#)
- [Draft of a Template Supplied by NIH](#)
- [Format, including citations, file names, file sizes font, hyperlinks, page limits, etc.](#)
- [6 main elements to include](#)
- [Budgeting for Data Management and Sharing](#)
- [Submitting Human Genomic Data](#)
- [NIH FAQ, including information on human data, and when data should or should not be shared](#)



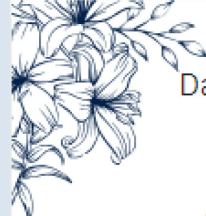
Reach out to Data Services

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- Help you prepare your data to be shared
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- Help you use other data software and tools
- Review your data management and sharing plan or your dataset

Visit our webpage to learn more about our services and our contact information: <https://www.library.rochester.edu/services/data-management-and-sharing>

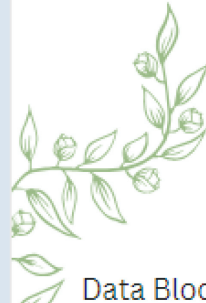




Data Bloom: Accessible and
Appealing Visualizations
9/18

Data Bloom: Cleaning and
Visualization with Excel [Windows]
10/9

Data Bloom: Data Visualization
with R
10/23



Data Bloom: Visualize with
Python
11/1

Data Bloom: Visualizing
Data with Special
Collections
11/12

Data Bloom: Using PivotTables and
PivotCharts in Excel [Mac]
11/18

Data Bloom: In 3D - XR for
Data Visualization
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Data Bloom: Cleaning and
Visualization with Excel [Mac]
10/11

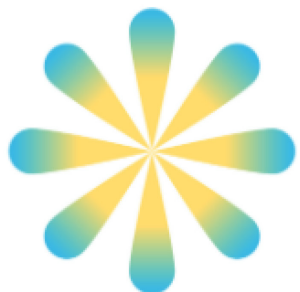
Data Bloom: Witch Map is
Which? A Spooky GIS Workshop
10/30

Data Bloom: Public Speaking
Skills in Data Presentation
11/7

Data Bloom: Using PivotTables
and PivotCharts in Excel
[Windows]
11/15

Data Bloom: Composing Stories
with Data and Viz in Tableau
11/20

Scan the QR code to register for a workshop and get more info on the
upcoming **Data Bloom Data Visualization Competition!**



Data Bloom



University
of Rochester
LIBRARIES



Remember Data Bloom!

- 9/18: Accessible and Appealing Visualizations
- 9/24: In 3D – XR for Data Visualization
- 10/9: Cleaning and Visualization with Excel [Windows]
- 10/11: Cleaning and Visualization with Excel [Mac]
- 10/23: Data Visualization with R
- 10/30: Witch Map is Which? A Spooky GIS Workshop
- 11/1: Visualize with Python
- 11/7: Public Speaking Skills in Data Presentation
- 11/12: Visualizing Data with Special Collections
- 11/15: Using PivotTables and PivotCharts in Excel [Windows]
- 11/18: Using PivotTables and PivotCharts in Excel [Mac]
- 11/20: Composing Stories with Data and Viz in Tableau

For more information go to our QR code or
to <https://libguides.lib.rochester.edu/data-bloom>

Please fill out our survey!

It will take only a few minutes.

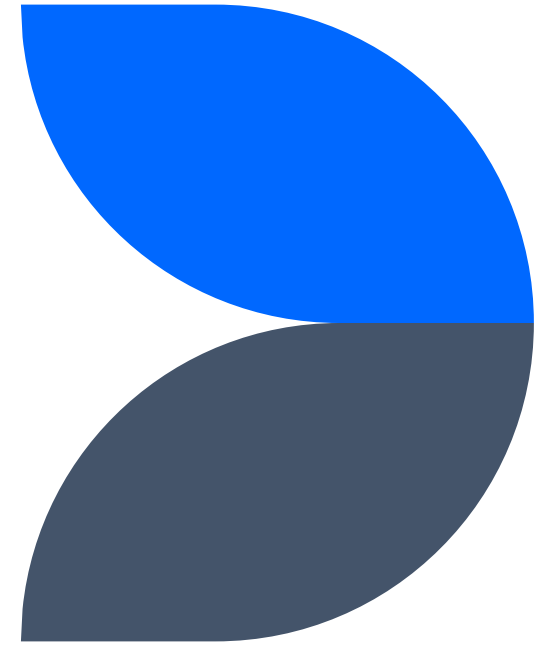


Thank you
very much!



https://rochester.libwizard.com/f/NIHDMSP_Survey

Q&A





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Member the of Data Services Team

[https://www.library.rochester.edu/services/
data-management-and-sharing](https://www.library.rochester.edu/services/data-management-and-sharing)

Thank you for coming!
Please contact us if you have any questions.

Question 1

I need to write a DMSP for the NIH, and I don't know where to start. My research involves genomic data.
Do you have any resources
that can help me?

Answer 1

- You can learn more about creating data management and sharing plans on the [Data Management and Sharing Service Webpage](#) and the [Miner Library Guide](#). We also have [templates](#) you can use. Additionally, we have institutional access to the [DMPTool](#), just make sure you login with your university email. Within this tool you have access to many templates, and you can submit your data management and sharing plan for review. You can also have your DMSP reviewed by emailing it to dataservices@library.rochester.edu.
- **For additional guidance on working with genomic data please also consult:**
- **Genomics Research Center:** URgenomics@urmc.rochester.edu

[Visit the UPMC Genomics Research Center website](#)

Question 2

I am not sure what data repository to use to share my data, and I need to include this information in my DMSP.

Answer 2

- You should use a subject-specific domain repository. You can find a list of NIH-approved subject-specific domain repositories here:
https://www.nlm.nih.gov/NIHbmic/domain_specific_repositories.html
- If you cannot find a suitable subject-specific domain repository, then you should use the University of Rochester Research Repository (URRR). URRR is the UR instance of Figshare, which is a generalist repository. You can find URRR at rochester.figshare.com. If you need any assistance, please feel free to reach out to the Data Management and Sharing Service.

Question 3

I'm not sure what data needs to be included in my DMSP. Can you provide some guidance on what types of data are typically included in these plans?

Answer 3

- Scientific data needs to be shared, which is defined as “any data needed to validate and replicate research findings.” This does not include such things as laboratory notebooks, preliminary analyses, compared case report forms, etc. You can learn more about this on the [NIH's page about research data](#).
- It is also understood that some data cannot be shared openly or even at all, due to certain ethical, legal, and social issues. You can read the list of accepted reasons on the [NIH's FAQ](#).
- If you decide you cannot share some of your scientific data, or if you will limit sharing, share the reason why in your DMSP.

Question 4

My research involves survey data. What are some generalist/domain specific repositories for this type of data?

Answer 4

- **ICPSR**: is a large repository of social science data, including medical survey data. Additionally, ICPSR (institutional access) allows users to assign different levels of access to their data, ensuring that any privacy or confidentiality concerns are addressed. (See also [NACDA](#) and [OPENICPSR](#))
- **Zenodo**: assigns a digital object identifier (DOI) to each dataset, making it easy to cite and access. In addition, users can assign a Creative Commons license to their data, making it clear how the data can be reused.
- **URRR**: Beyond the features above, Figshare also has a robust metadata system that makes it easy for others to discover and understand the data.