

Data Sharing

**Principles of Good Data-Sharing
Hygiene**

What are we
talking about?

The purpose of this is not to tell anyone how to conduct their research.
The purpose is to discuss concepts and best practices related to how you plan, organize, save, and share the data generated from your research

In this presentation you will learn:

- 1: Basic knowledge of how to share your data, including
 - How to select data repository
 - How to process data for sharing
 - Safeguarding your data
- 2: How to discover, request, reuse and cite data

2 sides of
sharing data

Data Creator



Prepare data for sharing
Deposit data in a repository
Safeguard data

Data Requester



Discover data
Acquire data
Cite other people's data

What is data?

NIH

National Institutes of Health

“Recorded factual material commonly accepted in the scientific community as necessary to document and support research findings”



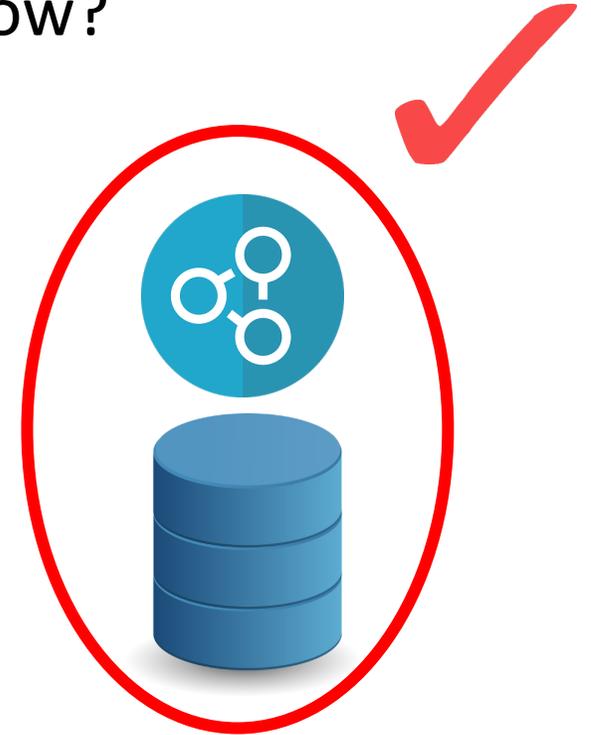
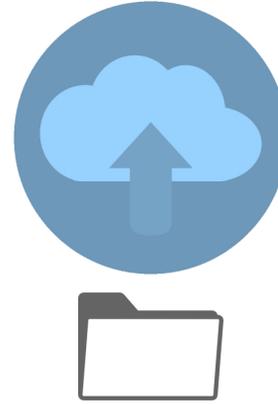
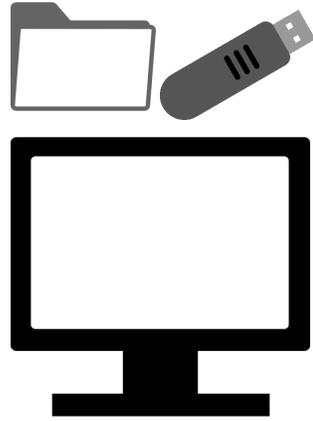
“determined by the community of interest through the process of peer review and program management”



NATIONAL
ENDOWMENT
FOR THE
HUMANITIES

“materials generated or collected during the course of conducting research”

Where is your data now?

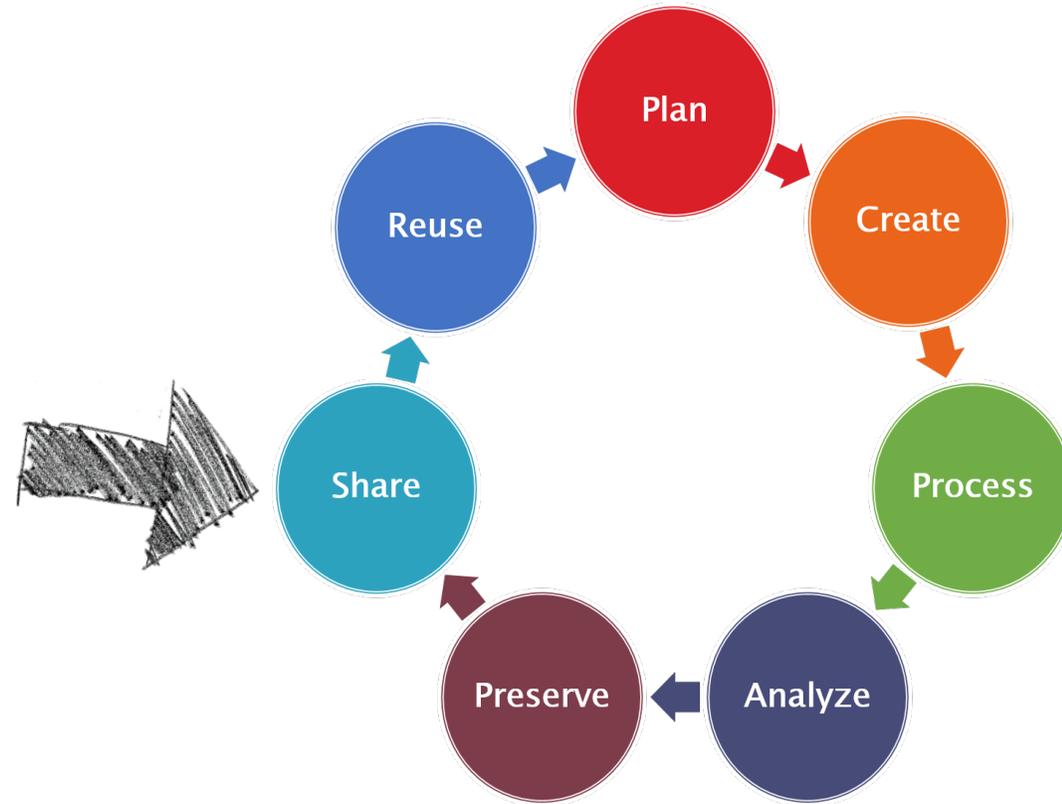


What is data sharing?

Storage?

Can anyone else find them and access them?

Do I have to share?



Is sharing data required (or prohibited) by your sponsor or funding agency?

Is sharing data supported by your research communities and/or publishers?

Sort by

Best Match

Recommended Records

Recommended

Associated Publication?

No Publication

Has Publication

Claimed?

No Maintainer

Has Maintainer

Record Status

Uncertain

Deprecated

In develop

Ready

Record Type

Journal 64

Funder 15

Project 4

Society 1

Domains

Bibliography 42

Registry	Name	Abbreviation	Type	Subject	Domain	Taxonomy	Related Database	Related Standard	Related Policy	In Collection/Recommendation	Status
	UK Biotechnology and Biological Sciences Research Council Data Sharing Policy	N/A	Funder	Biomedical Science Life Sciences	None	All	None	None	None	None	
	Cancer Research UK Policy on Data Sharing and Preservation	N/A	Funder	Biomedical Science Oncology	Cancer	All Homo sapiens	None	None	None	None	
	CDER Data Standards Plan Version 1.0	N/A	Funder	Biomedical Science Life Sciences Preclinical And Clinical Studies	Drug	Homo sapiens	None	None	None	None	
	Genome Canada Data Release and Resource Sharing Policy	N/A	Funder	Biomedical Science Life Sciences	DNA Sequence Data Genome Annotation Genome	All	None	None	None	None	
	Gordon and Betty Moore Foundation Data Sharing Philosophy and Plan	N/A	Funder	Biomedical Science Environmental Sciences Life Sciences	None	All	None	None	None	None	
	UK Medical Research Council Data Sharing Policy	N/A	Funder	Biomedical Science Life Sciences Preclinical And Clinical Studies	Experimentally Determined	Homo sapiens	None	None	None	None	

policies > doi:10.25504/fairsharing.gtah3b

Actions

Policy for Sharing of Data Obtained in US National Institutes of Health Supported or Conducted Genome-Wide Association Studies

Abbreviation: NIH GWAS Sharing Policy

General Information

Homepage <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-07-088.html>

Countries that developed this resource United States

Published in 2008

Type: Funder

Description:

Policy for accessing the individual level genomic data distributed through the dbGaP database.

Taxonomic range

Knowledge Domains

Subjects

User-defined Tags

How to cite this record FAIRsharing.org: Policy for Sharing of Data Obtained in US National Institutes of Health Supported or Conducted Genome-Wide Association Studies; DOI: 10.25504/FAIRsharing.gtah3b; Last edited: Jan. 8, 2019, 1:41 p.m.; Last accessed: Apr 25 2019 9:22 p.m.

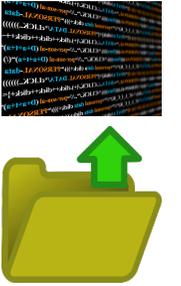
This record is maintained by luninghao

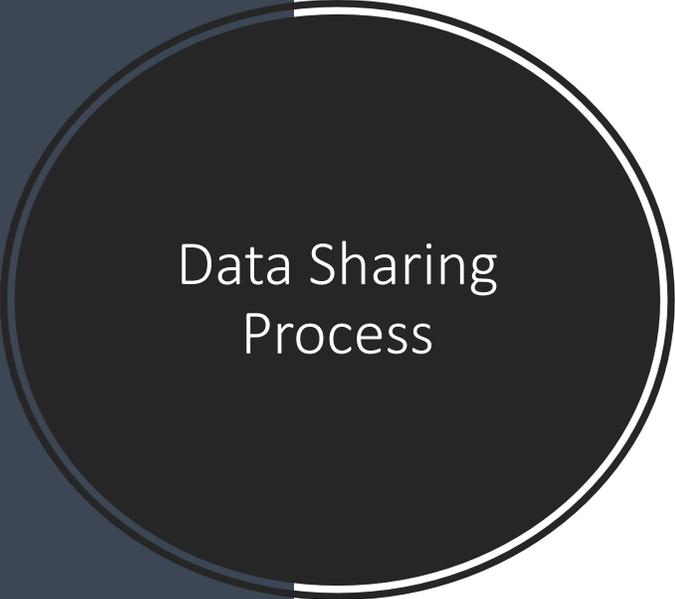
Record updated: Nov. 21, 2018, 10:54 a.m. by The FAIRsharing Team.

Show edit history

Data Sharing Process

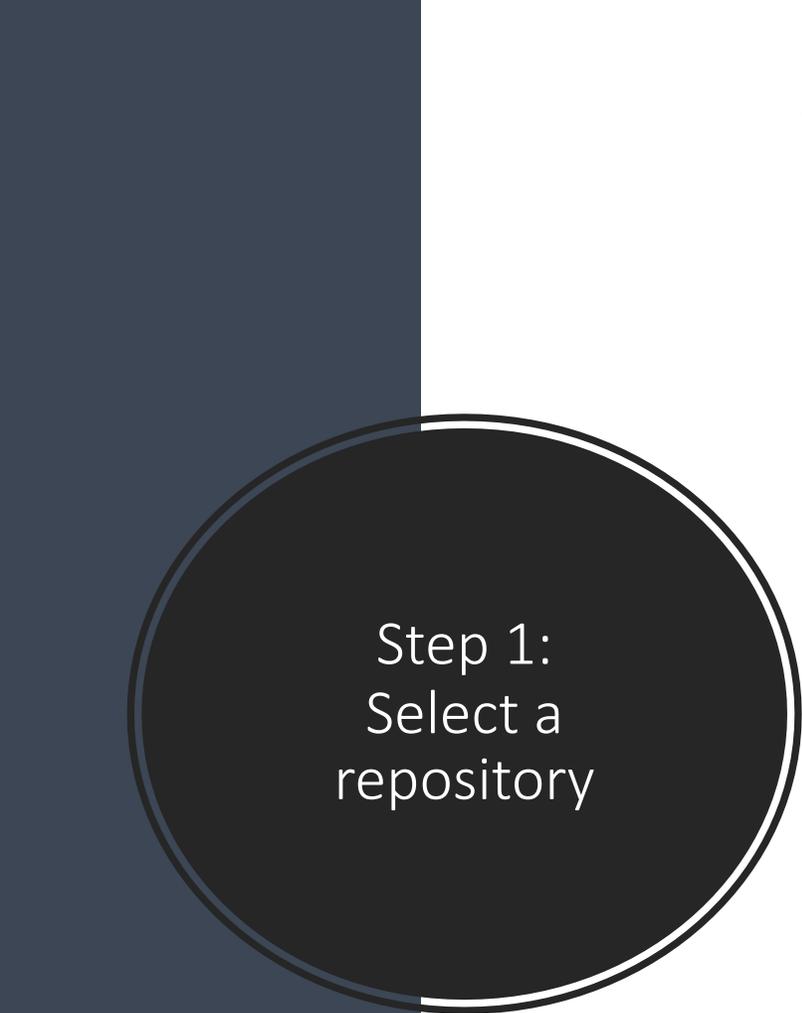
- 1: Select a repository
- 2: Prepare data for preservation and reuse
- 3: Safeguard and monitor use of your data





Data Sharing
Process

Step 1: Select data repository



Step 1:
Select a
repository

What is a Data Repository?

“subtype of a sustainable information infrastructure which provides long-term storage and access to research data that is the basis for a scholarly publication.”

- Institutional repository
- General repository
- Subject specific repository

Selecting the right repository for your data is as important as selecting the right journal for your manuscript!

The Registry of Research Data Repositories <https://www.re3data.org/>

OpenDOAR (Directory of Open Access Repositories) <http://v2.sherpa.ac.uk/opensoar/>

Institutional Data Repositories

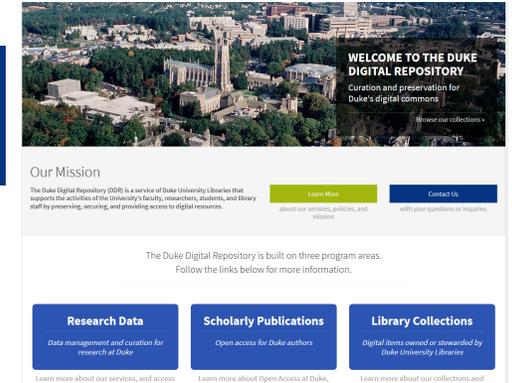
Institutional Repository @ RU



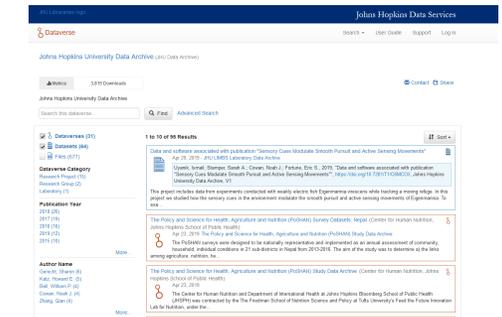
Step 1:
Select a
repository



<https://repository.duke.edu/>



<https://archive.data.jhu.edu/>



<https://www.library.cmu.edu/kilthub/about>



General Data Repositories



[Dryad](#)



figshare

[Figshare](#)



[Harvard Dataverse](#)

The Zenodo logo is the word "zenodo" in white lowercase letters on a blue rectangular background.

zenodo

[Zenodo](#)

Step 1:
Select a
repository

Subject Specific Data Repository <https://www.nature.com/sdata/policies/repositories>

Step 1:
Select a
repository

Repository Name	Repository URL	Type of repository
The Network Data Exchange (NDEx)	www.ndexbio.org	Biological sciences: mathematical & modelling resources
Functional Connectomes Project International Neuroimaging Data-Sharing Initiative	http://fcon_1000.projects.nitrc.org/	Biological sciences: neuroscience
G-Node	https://web.gin.g-node.org/	Biological sciences: neuroscience
NeuroMorpho.org	http://neuromorpho.org/neuroMorpho/index.jsp	Biological sciences: neuroscience
OpenNeuro	https://openneuro.org/	Biological sciences: neuroscience
Database of Genomic Variants Archive	http://www.ebi.ac.uk/dgva/	Biological sciences: nucleic acid sequence
dbSNP	http://www.ncbi.nlm.nih.gov/snp	Biological sciences: nucleic acid sequence
dbVar	http://www.ncbi.nlm.nih.gov/dbvar/	Biological sciences: nucleic acid sequence
DNA DataBank of Japan	http://www.ddbj.nig.ac.jp/	Biological sciences: nucleic acid sequence
EBI Metagenomics	http://www.ebi.ac.uk/metagenomics	Biological sciences: nucleic acid sequence
European Nucleotide Archive	http://www.ebi.ac.uk/ena/	Biological sciences: nucleic acid sequence
European Variation Archive	http://www.ebi.ac.uk/EVA	Biological sciences: nucleic acid sequence
GenBank	http://www.ncbi.nlm.nih.gov/genbank/	Biological sciences: nucleic acid sequence
NCBI Assembly	http://www.ncbi.nlm.nih.gov/assembly	Biological sciences: nucleic acid sequence
NCBI Sequence Read Archive	http://www.ncbi.nlm.nih.gov/sra	Biological sciences: nucleic acid sequence
NCBI Trace Archive	http://www.ncbi.nlm.nih.gov/Traces/home/	Biological sciences: nucleic acid sequence
BioModels Database	http://biomodels.net/	Biological sciences: mathematical & modelling resources
Kinetic Models of Biological Systems	http://www.kimosys.org/	Biological sciences: mathematical & modelling resources
FlowRepository	https://flowrepository.org/	Biological sciences: cytometry & immunology
ImmPort	www.immport.org	Biological sciences: cytometry & immunology
Image Data Resource	http://idr.openmicroscopy.org/about/	Biological sciences: imaging
Biological Magnetic Resonance Data Bank	http://www.bmrb.wisc.edu/	Biological sciences: molecular & supramolecular structure
Coherent X-ray Imaging Data Bank	http://www.cxidb.org/	Biological sciences: molecular & supramolecular structure
Crystallography Open Database	http://www.crystallography.net/	Biological sciences: molecular & supramolecular structure
EMDataBank	http://www.emdatabank.org/	Biological sciences: molecular & supramolecular structure
Protein Circular Dichroism Data Bank	http://pcddb.cryst.bbk.ac.uk/	Biological sciences: molecular & supramolecular structure
Structural Biology Data Grid	https://data.sbgrid.org/	Biological sciences: molecular & supramolecular structure
Worldwide Protein Data Bank	http://wwpdb.org/	Biological sciences: molecular & supramolecular structure

Subject Specific Data Repository

NIH supported Data Sharing Repositories

https://www.nlm.nih.gov/NIHbmic/nih_data_sharing_repositories.html

NIH Data Sharing Repositories

This table lists NIH-supported data repositories that make data accessible for reuse. Most accept submissions of appropriate data from NIH-funded investigators (and others), but some restrict data submission to only those researchers involved in a specific research network. Also included are resources that serve as a portal for information about biomedical data and information sharing systems. The table can be sorted by repository name and by NIH Institute or Center and may be searched using keywords so that you can find repositories more relevant to your data. Links are provided to information about submitting data to and accessing data from the listed repositories. Also, we have asked all repositories to indicate whether or not they have— current NIH funding support; open data submission; open data access; open time frame for data submission; and sustained support. Their Yes or No responses are included in the five columns to the right of the table. *The information in the BMIC list is also available in a [downloadable Excel version](#).*

In our *query* to the repositories, we acknowledged that some repositories may have restrictions or limitations on data submission and requirements for data access. Additional information about the repositories and points-of-contact for further information or inquiries can be found on the websites or links shown for each. *Are we missing a data sharing repository that should be included in this list? **Do you have comments or feedback on this list or the website?** [Contact us](#).*

Show entries

Search:

ICO	Repository Name	Repository Description	Data Submission Policy	Access to Data	Current NIH funding support	Open data submission	Open data access	Open time frame for data deposit	Sustained support
Common Fund	Epigenomics	Epigenomic, 6 histone modification marks, DNase I, DNA methylation, transcriptome for wide variety of cell types and tissues.	Not applicable	How to access Epigenomics data	No	No	Yes	No	Yes
Common Fund	exRNA Atlas	Includes exRNA profiles derived from various biofluids and conditions and currently stores data profiled from small RNA sequencing assays.	Not applicable	How to access exRNA Atlas data	Yes	No	Yes	No	Yes
		The Cancer Tissue Expression							

Step 1:
Select a
repository

Key elements to consider when selecting a repository

Step 1:
Select a
repository

Can you get a unique identifier?

Does it give your submitted dataset a persistent and unique identifier, such as DOI (Digital Object Identifier)? Does it provide guidance on how to cite the data that has been deposited?

Is the repository a reputable source?

Is it endorsed by a funding agency, scholarly journal, professional society?

Is the repository sustainable?

Does the repository have the support of an institution, community, or funder? Does it have preservation plans and contingency plans in the event that outside funding is ceased.

Does it have features you need?

Does it integrate with external storage solutions? What are the limits on storage? Does it monitor how many times your data set is used? Does it support technical and metadata standards?

Does it have clear Terms and Conditions?

What permissions are you giving the data repository? Do the terms and conditions meet legal requirements (e.g. for data protection)?

Does it provide security your data need?

Are operating systems, other core infrastructural software, and technologies appropriate to the services it provides? Does it provide protection to the facility and its data, products, services, and users?





Step 1: Select a repository

- R1. The repository has an explicit mission to provide access to and preserve data in its domain.
- R2. The repository maintains all applicable licenses covering data access and use and monitors compliance.
- R3. The repository has a continuity plan to ensure ongoing access to and preservation of its holdings.
- R4. The repository ensures, to the extent possible, that data are created, curated, accessed, and used in compliance with disciplinary and ethical norms.
- R5. The repository has adequate funding and sufficient numbers of qualified staff managed through a clear system of governance to effectively carry out the mission.
- R6. The repository adopts mechanism(s) to secure ongoing expert guidance and feedback (either in-house, or external, including scientific guidance, if relevant).
- R7. The repository guarantees the integrity and authenticity of the data.
- R8. The repository accepts data and metadata based on defined criteria to ensure relevance and understandability for data users.
- R9. The repository applies documented processes and procedures in managing archival storage of the data.
- R10. The repository assumes responsibility for long-term preservation and manages this function in a planned and documented way.
- R11. The repository has appropriate expertise to address technical data and metadata quality and ensures that sufficient information is available for end users to make quality related evaluations.
- R12. Archiving takes place according to defined workflows from ingest to dissemination.
- R13. The repository enables users to discover the data and refer to them in a persistent way through proper citation.
- R14. The repository enables reuse of the data over time, ensuring that appropriate metadata are available to support the understanding and use of the data.
- R15. The repository functions on well-supported operating systems and other core infrastructural software and is using hardware and software technologies appropriate to the services it provides to its designated Community.
- R16. The technical infrastructure of the repository provides for protection of the facility and its data, products, services, and users.

In Sum:

Step 1:
Select a
repository

1. Check your policies
Some agencies, policies, grants, or journals may specify or suggest where data should be deposited.



<https://fairsharing.org/>

2. Consider institutional repository, discipline-specific, or research model-specific repositories

➔ NIH Supported Data Sharing Repositories
https://www.nlm.nih.gov/NIHbmic/nih_data_sharing_repositories.html

➔ Subject Specific Data Repository
<https://www.nature.com/sdata/policies/repositories>

3. Turn to a general data repository if no discipline-specific or research model-specific one exists



[Dryad](#)

[Figshare](#)

[Harvard Dataverse](#)

[Zenodo](#)

4. Evaluate repository of choice

Step 2
Prepare your
data

Step 2: Prepare your data

What data to keep? Five steps to decide what data to keep



Step 2 Prepare your data

- **What data and for how long?**
Source data, Assembled datasets, or Referenced data?
- **Step 1. Identify purposes that the data could fulfill**
Verification, Further analysis, Building academic reputation, Community resource development, Further publications, Learning & teaching, Private use.
- **Step 2. Identify data that must be kept**
How valuable the data is for the purposes identified above? Is there any relevant funder or institutional policies? Do regulations require the data to be available? Legal or contractual reasons? Does it contain personal data relevant to the reuse purpose?
- **Step 3. Identify data that should be kept**
Is it good enough? Quality of data? Is there likely to be a demand? Would reproducing the data be difficult/costly? Are any restrictions? Could the data have broad appeal?
- **Step 4. Weigh up the costs**
Is funding available to pay any charges for storage and curation beyond the research period?
- **Step 5. Complete the data appraisal**
Summarize the outcomes of above steps.

What data will be shared?

Intellectual property: Who does the data belong to? You? Institution? Funder?

Uniqueness of data: Can it be easily duplicated?

Private and confidential data: Will individual-level data or raw data also be shared, and if so, will the whole data set be shared? De-identified for IPD? Do you have consent to share de-identified data?

Who and when will data be accessed: When will data be released? General public can access it or limited to qualified researchers?



Conditions for reuse!

Refer back to your Data Management Plan!

Step 2
Prepare your
data

Sensitive data?

Sensitive data is data that must be protected against unwanted disclosure.



Personal data:

https://privacyruleandresearch.nih.gov/pr_08.asp

Confidential data:

Trade secrets, data protected by intellectual property rights, Security passwords, financial information, national safety, military information...

Biological data:

Endangered (plant or animal) species, where their survival is dependent on the protection of their location data (biodiversity community)

Combination of different datasets

<https://www.openaire.eu/sensitive-data-guide>

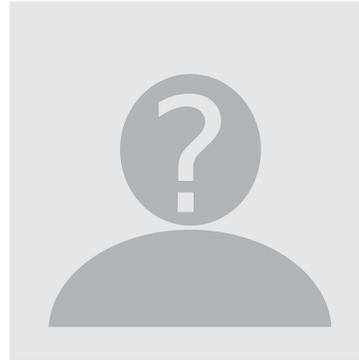
Step 2
Prepare your
data

Sensitive data?

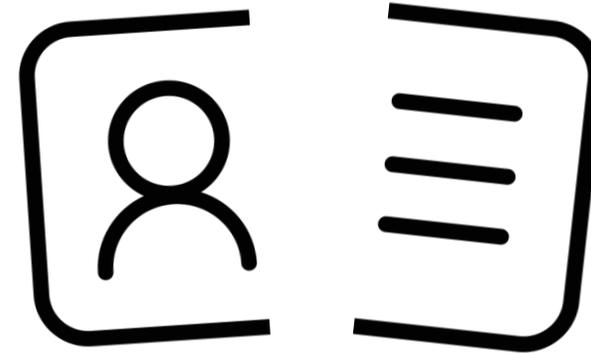
Personal data: https://privacyruleandresearch.nih.gov/pr_08.asp

Step 2
Prepare your
data

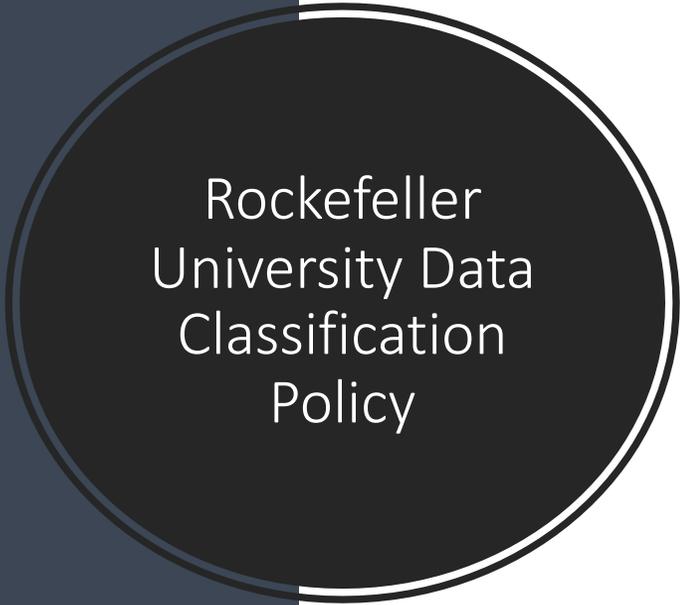
Anonymization



Pseudonymization



Encryption

A dark blue vertical bar on the left side of the slide contains a black circle with a white border. Inside the circle, the text "Rockefeller University Data Classification Policy" is written in white, centered.

Rockefeller
University Data
Classification
Policy

Successful data sharing relies on properly classifying your data so you understand the level of sensitivity of your data.

The Rockefeller University IT Department has a comprehensive Data Classification Policy that can provide important guidance on how to classify your data and the steps you can take to protect it while you are sharing it.

For more information refer to
<http://it.rockefeller.edu/data-classifications>

Prepare your sensitive data for sharing

Removing or recoding information

1) Locate and remove direct identifiers

2) Remove or recode geographic variables, to the broadest region required for analysis, rarely below State.

3) Scramble your data

Resort and renumber records and IDs from external source data and IDs created for your study.

Other statistical techniques could be appropriate for larger population quantitative data, including: top/bottom Coding limiting upper or lower ranges, collapsing categories into broader ranges, or swapping certain analytically comparable variables.

4) Remove / recode indirect variables such as those that pose risk of link to external datasets that could have matching values.

Step 2
Prepare your
data

*Document what you did to your sharing copy of your data, **keep it encrypted, offline or firewalled.***

*If data w/identifiers is needed for future research, **keep it encrypted, offline or firewalled.***

Clinical Text De-identification: <https://scrubber.nlm.nih.gov/>

Step 3
Safeguard your
data

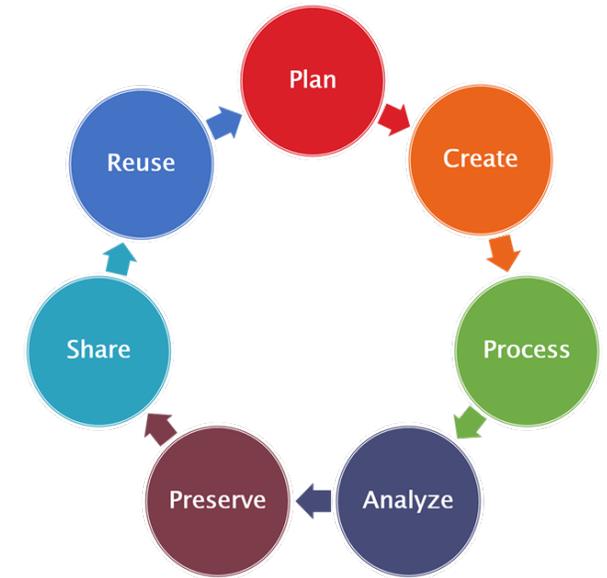
Step 3: Safeguard your data

Safeguarding your data in your environment

Data Curator



Step 3
Sharing your
data



The management of data throughout its lifecycle

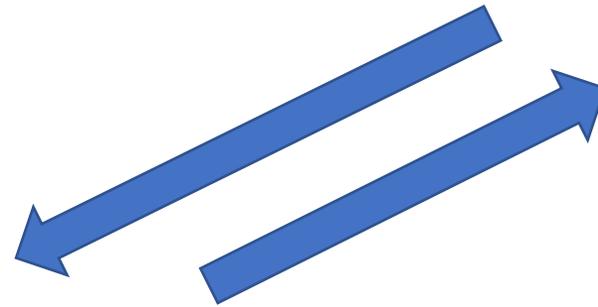
Manage data flow in the lab/research project

Maintaining and managing metadata

Make sure data standards are followed

Safeguarding your data in clinical setting

Your data in repository

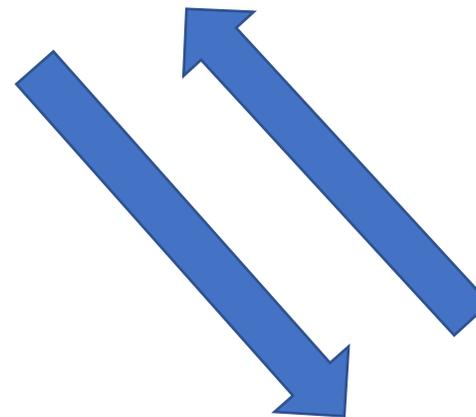


Step 3
Sharing your
data

Data Curator

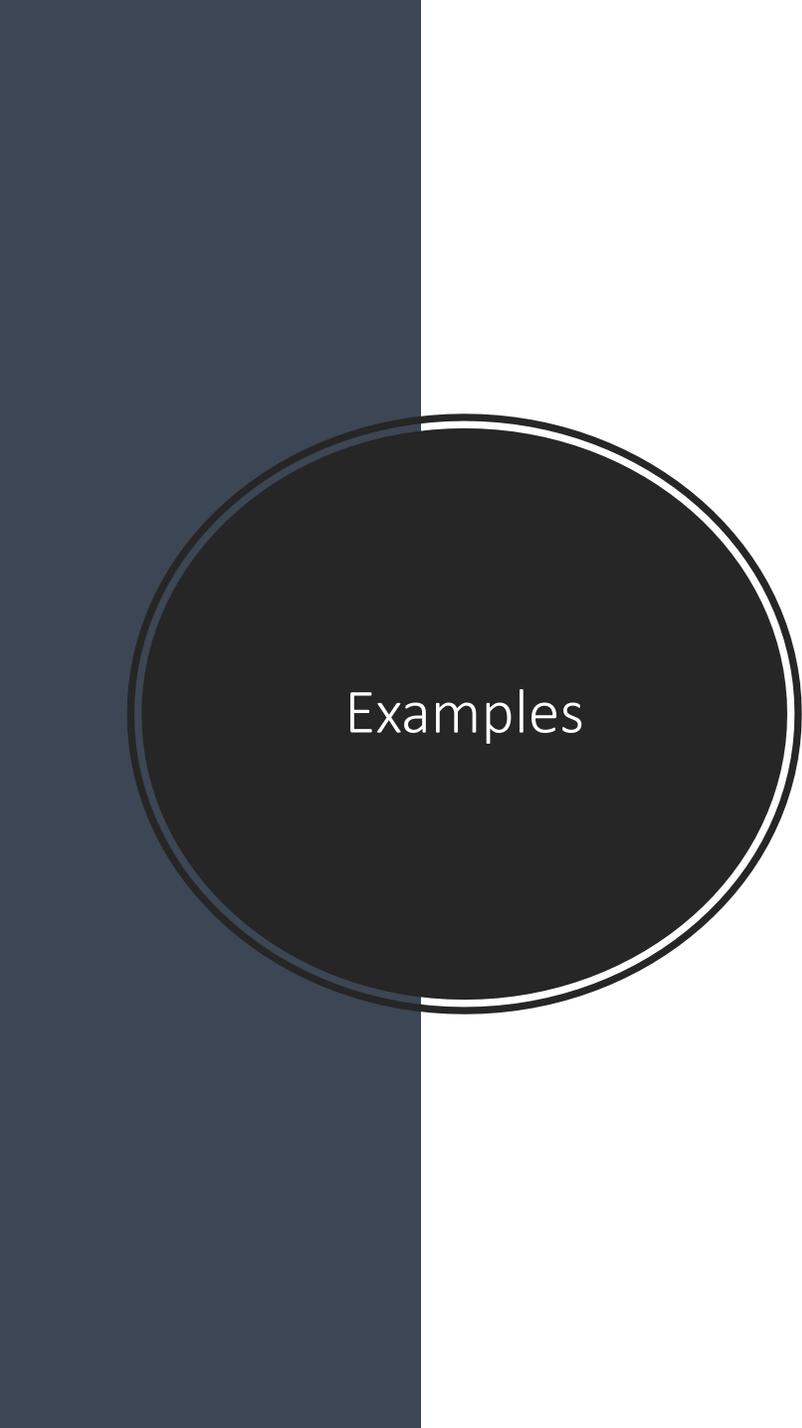


- Gate keeper for clinical data
- Make sure to follow data license/agreement
- Keeping track of external regulations and compliance
- Make sure that de-identification is complete
- Make sure that data transaction is secured



Requestor





Examples

How to write data sharing plan

◀ PREVIOUS ARTICLE | THIS ISSUE | NEXT ARTICLE ▶
 EDITORIALS | 4 JULY 2017

Data Sharing Statements for Clinical Trials: A Requirement of the International Committee of Medical Journal Editors FREE

Darren B. Taichman, MD, PhD; Peush Sahni, MBBS, MS, PhD; Anja Pinborg, MD; Larry Peiperl, MD; Christine Laine, MD, MPH; Astrid James, MBBS; Sung-Tae Hong, MD, PhD; Abraham Haileamlak, MD; Laragh Gollogly, MD, MPH; Fiona Godlee, FRCP; Frank A. Frizelle, MBChB, FRACS; Fernando Florenzano, MD; Jeffrey M. Drazen, MD; Howard Bauchner, MD; Christopher Baethge, MD; Joyce Backus, MSLS
 Article, Author, and Disclosure Information

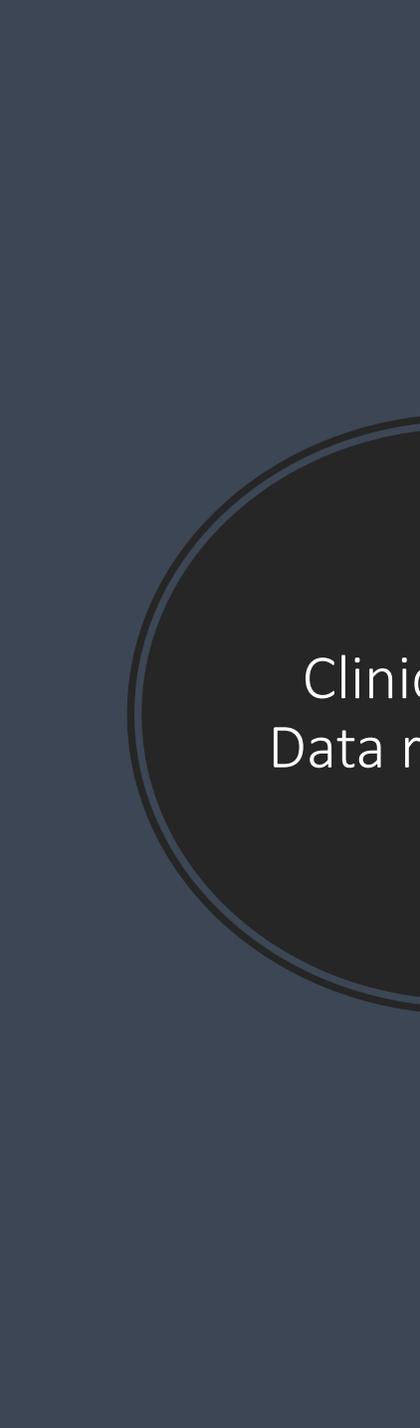
Data Sharing statement:

- 1) Would IPD shared?
- 2) What data in particular would be shared?
- 3) Additional related documents available?
- 4) When the data will become available, and for how long?
- 5) What access criteria data will be shared?

Table. Examples of Data Sharing Statements That Fulfill These ICMJE Requirements*

	Example 1	Example 2	Example 3	Example 4
Will individual participant data be available (including data dictionaries)?	Yes	Yes	Yes	No
What data in particular will be shared?	All of the individual participant data collected during the trial, after deidentification.	Individual participant data that underlie the results reported in this article, after deidentification (text, tables, figures, and appendices).	Individual participant data that underlie the results reported in this article, after deidentification (text, tables, figures, and appendices).	Not available
What other documents will be available?	Study Protocol, Statistical Analysis Plan, Informed Consent Form, Clinical Study Report, Analytic Code	Study Protocol, Statistical Analysis Plan, Analytic Code	Study Protocol	Not available
When will data be available (start and end dates)?	Immediately following publication. No end date.	Beginning 3 months and ending 5 years following article publication.	Beginning 9 months and ending 36 months following article publication.	Not applicable
With whom?	Anyone who wishes to access the data.	Researchers who provide a methodologically sound proposal.	Investigators whose proposed use of the data has been approved by an independent review committee ("learned intermediary") identified for this purpose.	Not applicable
For what types of analyses?	Any purpose.	To achieve aims in the approved proposal.	For individual participant data meta-analysis.	Not applicable
By what mechanism will data be made available?	Data are available indefinitely at (<i>Link to be included</i>).	Proposals should be directed to xxx@yyy. To gain access, data requestors will need to sign a data access agreement. Data are available for 5 years at a third party website (<i>Link to be included</i>).	Proposals may be submitted up to 36 months following article publication. After 36 months the data will be available in our University's data warehouse but without investigator support other than deposited metadata. Information regarding submitting proposals and accessing data may be found at (<i>Link to be provided</i>).	Not applicable

Clinical Trials
data



Clinical Trials
Data repository

ClinicalStudyDataRequest.com (CSDR) <https://www.clinicalstudydatarequest.com/Default.aspx>

Yoda data project <https://yoda.yale.edu/>

Vivli <https://vivli.org/>

Key Elements to Consider in Preparing a Data Sharing Plan Under NIH Extramural Support

https://www.nlm.nih.gov/NIHbmic/data_sharing_plan.html

How to write a
data sharing
plan

1. What data will be shared?
2. Who will have access to the data?
3. Where will the data to be shared be located?
4. When will the data be shared?
5. How will researchers locate and access the data?

Example Plan addressing Key Elements for a Data Sharing Plan under NIH Extramural Support
(For questions, contact the NIH Office of Extramural Research (OER), Email Sharing@nih.gov)

Example Data Sharing Plan for FOA-XX-XXXX

What data that will be shared:

I will share phenotypic data associated with the collected samples by depositing these data at _____ which is an NIH-funded repository. Genotype data will be shared by depositing these data at _____. Additional data documentation and de-identified data will be deposited for sharing along with phenotypic data, which includes demographics, family history of XXXXXX disease, and diagnosis, consistent with applicable laws and regulations. I will comply with the NIH GWAS Policy and the funding IC's existing policies on sharing data on XXXXXX disease genetics to include secondary analysis of data resulting from a genome wide association study through the repository. Meta-analysis data and associated phenotypic data, along with data content, format, and organization, will be available at _____. Submitted data will confirm with relevant data and terminology standards.

Who will have access to the data:

I agree that data will be deposited and made available through _____ which is an NIH-funded repository, and that these data will be shared with investigators working under an institution with a Federal Wide Assurance (FWA) and could be used for secondary study purposes such as finding genes that contribute to process of XXXXXX. I agree that the names and Institutions of persons either given or denied access to the data, and the bases for such decisions, will be summarized in the annual progress report. Meta-analysis data and associated phenotypic data, along with data content, format, and organization, will be made available to investigators through _____.

Where will the data be available:

I agree to deposit and maintain the phenotypic data, and secondary analysis of data (if any) at _____, which is an NIH-funded repository and that the repository has data access policies and procedures consistent with NIH data sharing policies.

When will the data be shared:

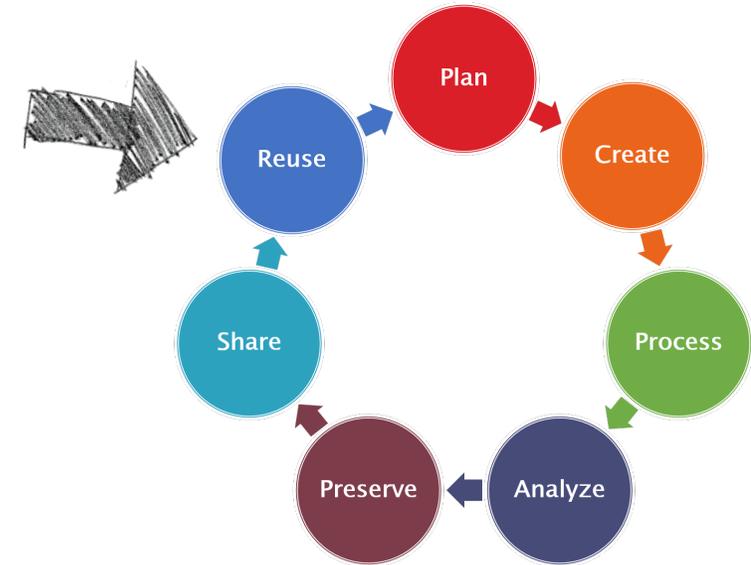
I agree to deposit genetic outcome data into _____ repository as soon as possible but no later than within one year of the completion of the funded project period for the parent award or upon acceptance of the data for publication, or public disclosure of a submitted patent application, whichever is earlier.

How will researchers locate and access the data:

I agree that I will identify where the data will be available and how to access the data in any publications and presentations that I author or co-author about these data, as well as acknowledge the repository and funding source in any publications and presentations. As I will be using _____, which is an NIH-funded repository, this repository has policies and procedures in place that will provide data access to qualified researchers, fully consistent with NIH data sharing policies and applicable laws and regulations.

Rev. 20100831

Reusing data



1. Discover data
2. Acquire data
3. Reuse and Cite data

Discover data



Finding data

1) Search in a Data Repositories / Data catalogs

<https://datacatalog.med.nyu.edu/>

<https://data.cdc.gov/browse>, <https://www.data.gov/>

<https://datadashboard.fda.gov/ora/index.htm>, <https://opendata.cityofnewyork.us/> etc..

2) Identify Potential Producers

Search institutional depository

Search in subject specific repositories

3) Turn to the literature

Ask for help!! Markus
Library x8904

<https://journals.plos.org/ploscompbiol/article?id=10.1371/journal.pcbi.1006038>

Acquire data



Acquire data

Check the data license

What datasets are available, when would it become available, who to contact, how to gain access, what is allowed to do with the data, do you have to pay?

Security requirement

Does that contain sensitive information? Any additional security required?

Using and citing data

Read supplemental documents

Data dictionary, Read me files, etc..

Data cleanup

Is it organized well? Can you run your analysis?

Citing data

Minimum :

Creator (PublicationYear). Title. Publisher. Identifier

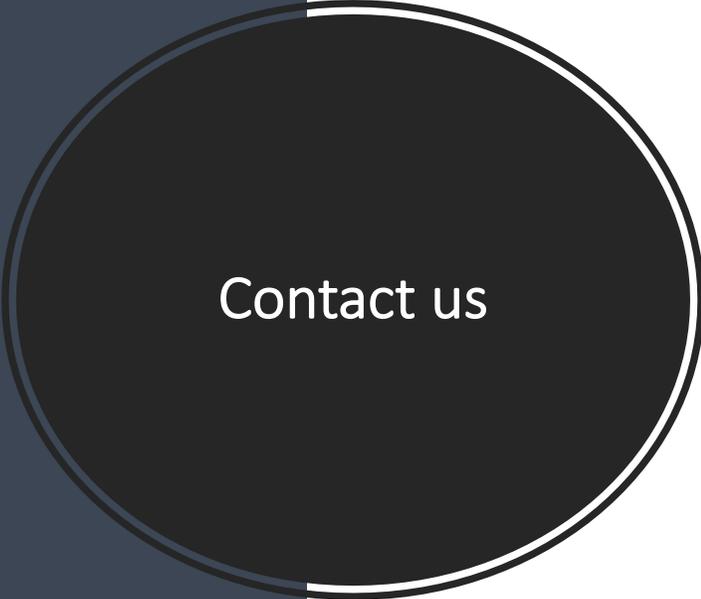
Preferred:

Creator (PublicationYear). Title. Version. Publisher. ResourceType.
Identifier

Example from Duke Digital Repository

Zhuang, Y. and Charbonneau, P. (2018). Data and scripts from: Equilibrium phase behavior of the square-well linear microphase-forming model. Duke Digital Repository. V2 <https://doi.org/10.7924/r42z16837>

Reuse and cite
data



Contact us

For more information on Data Management please contact the following staff at the Rita and Frits Markus Library

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