

Preparing for the New NIH Data Management and Sharing Plan: Session 2 - Where to Share Data

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UNIVERSITY OF
SOUTH ALABAMA

New NIH Data Management and Sharing Policy



<https://livingnewdeal.org/projects/national-institutes-of-health-campus-bethesda-md/>

- **NIH Data Management and Sharing(DMS) Policy** goes into effect on January 25, 2023.
- Goal to promote the sharing of scientific data and create a **consistent minimum expectation** for all research supported by the NIH.

Why share data?

- Sharing scientific data accelerates research discovery by enabling the validation of research results, providing accessibility to high-value datasets, and promoting data reuse for future research studies.

Elements of a DMS Plan

Plan Elements

Data Type

Identify data and metadata to be preserved and shared

Tools, Software, Code

Tools and software needed to access and manipulate data

Standards

Standards to be applied to scientific data and metadata

Data Preservation, Sharing, Timelines

Repository to be used, persistent unique identifier, and when/how long data will be available

Access, Distribution, Reuse

Description of factors for data access, distribution, or reuse

Oversight

Plan compliance will be monitored/managed and by whom

New Info for DMS Plan: No Hypertext

- **Do not** include hypertext in the DMS Plans and attachments.
 - hyperlinks and URLs
- NIH may withdraw your application from consideration if hypertext is included.
- For Example, in DMS Plan, you should include the name of the proposed data repository but **do not** provide the link or URL.
- For more guidance on what to include, see NIH's **Writing a Data Management & Sharing Plan** page and NIH's hyperlink policy
 - <https://nexus.od.nih.gov/all/2019/05/13/the-dos-donts-of-hyperlinks-in-grant-applications/>



<https://sharing.nih.gov/data-management-and-sharing-policy/planning-and-budgeting-for-data-management-and-sharing/writing-a-data-management-and-sharing-plan#data-management-and-sharing-plan-format>

NIH Data Sharing Landscape

Research Data Repositories

NIH encourages the use of established Data Repositories

Data repository: is a centralized location where data are curated, preserved, and made accessible.

Data repositories are best suited to oversee the long-term storage and preservation of data.

Repositories have specific data management requirements:

- accepted file types
- metadata standards
- documentation requirements (e.g., data dictionaries, code keys, data sharing consent forms)
- associated costs

Researchers need to determine the appropriate data repository when writing their DMS plan.

Cannot be done at the end of the project!



<https://www.infoday.com/cilmag/apr16/Uzwyshyn--Research-Data-Repositories.shtml>

Selecting a Data Repository

- Types of Repositories Available:
 - Subject or Discipline-Specific Repository
 - Generalist Repository
 - Institutional Repository
- Repository selection should be based on:
 - sensitivity of the data
 - size and complexity of the dataset
 - anticipated data usage
- **There is no one-size fits all repository!**



<https://www.mbrouns.com/posts/2020-02-20-prior-has-some-potential/>

Considerations for Selecting a Repository

- To the greatest extent possible, data repositories should follow best practices for data management and stewardship that maximize the principles of **FAIR Data Sharing**

Findable

- Data and supplementary materials have sufficiently rich metadata and a unique and persistent identifier.

Accessible

- Metadata and Data are understandable to humans and machines. Data is deposited in a trusted repository.

Interoperable

- Metadata use a formal, accessible, shared, and broadly applicable language for knowledge representation.

Resuable

- Data and collections have a clear usage licenses and provide accurate information on provenance.

Desirable Characteristics for All Data Repositories

❖ Characteristics determined by the NIH and the National Science and Technology Council.

Unique Persistent Identifiers	<ul style="list-style-type: none">• Assigns a citable, unique persistent identifier to datasets to support data discovery, reporting, and research assessment.
Long-Term Sustainability	<ul style="list-style-type: none">• Long-term plan for managing data; stable technical infrastructure and funding plans; contingency plans in case of unforeseen events.
Metadata	<ul style="list-style-type: none">• Ensures datasets are accompanied by metadata to enable discovery, reuse, and citation.
Curation and Quality Assurance	<ul style="list-style-type: none">• Provides expertise to improve the accuracy and integrity of datasets and metadata.
Free and Easy Access	<ul style="list-style-type: none">• Provides maximally open access, consistent with legal and ethical limits.
Broad and Measured Reuse	<ul style="list-style-type: none">• Makes datasets and their metadata available with broadest possible terms of reuse; enables data tracking.

Desirable Characteristics for All Data Repositories continued

Clear Use Guidance	<ul style="list-style-type: none">• Provides accompanying documentation describing terms of dataset access and use.
Security and Integrity	<ul style="list-style-type: none">• Documented measures in place to meet accepted criteria for preventing unauthorized access, modification, or release of data, with security levels appropriate to the sensitivity of data.
Confidentiality	<ul style="list-style-type: none">• Documented capabilities for ensuring confidentiality, risk management, and continuous monitoring for sensitive data.
Common Format	<ul style="list-style-type: none">• Datasets and metadata can be downloaded, accessed, or exported in a standards-compliant format.
Provenance	<ul style="list-style-type: none">• Mechanisms in place to record the origin, chain of custody, and any modifications to submitted datasets and metadata.
Retention Policy	<ul style="list-style-type: none">• Provides documentation on policies for data retention within the repository.



Additional Considerations for Human Data

❖ Additional repository characteristics for human participant data **even if data are de-identified.**

Fidelity to Consent

- Documented procedures to restrict dataset access and uses consistent with original consent.

Restricted Use Compliant

- Documented procedures to communicate and enforce data use restrictions.

Privacy

- Implements and provides documentation of measures to protect human subjects' data from inappropriate access.

Plan for Breach

- Security measures that include a response plan for detected data breaches.

Download Control

- Controls and audits access to and download of datasets.

Violations

- Procedures for addressing violations of terms-of-use by users and data mismanagement by the repository.

Request Review

- Makes use of an established and transparent process for reviewing data access requests.

Determining Repository Trustworthiness

Trustworthy Repositories

- ❖ Repositories can demonstrate their trustworthiness by adhering to the **TRUST Principles for Data Repositories.**

Transparency

- To be transparent about specific repository services and data holdings that are verifiable by publicly accessible evidence.

Responsibility

- To be responsible for ensuring the authenticity and integrity of data holdings and for the reliability and persistence of its service.

User Focus

- To ensure that the data management norms and expectations of target user communities are met.

Sustainability

- To sustain services and preserve data holdings for the long-term.

Technology

- To provide infrastructure and capabilities to support secure, persistent, and reliable services.

Demonstrating Trustworthiness

- Repositories also demonstrate their trustworthiness through a process of audit and certification.
- Certification allows data repositories to demonstrate that an independent authority has evaluated and endorsed its trustworthiness.
- Ensures reliability and durability of data repositories.



www.vectorstock.com/16163373

Three Primary Sources for Certification

Core Trust Seal (CTS)

Combination of Data Seal of Approval (DSA) and World Data System (WDS) certifications.



<https://www.coretrustseal.org/>



Nestor Seal

Network of expertise in long-term storage of digital resources in Germany. Nestor Seal certification is granted based on a structured external review and publicly available self audit.

https://www.langzeitarchivierung.de/Webs/nestor/EN/nestor/ueber_uns/ueber_uns_node.html



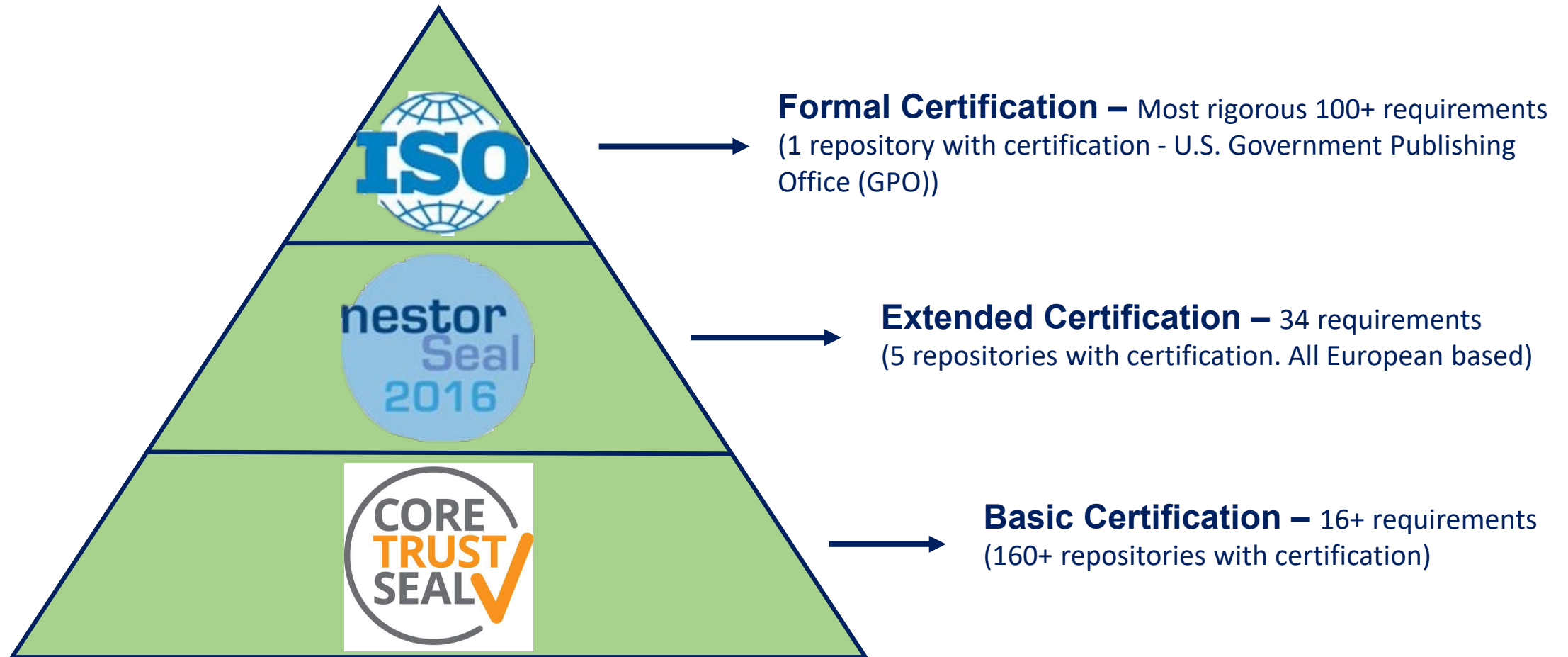
ISO 16363

International Organization for Standardization. The world's largest developer of international standards used by Government, business and new information technology companies. Full external audit.

<http://www.iso16363.org/>



Certifications of Trustworthiness



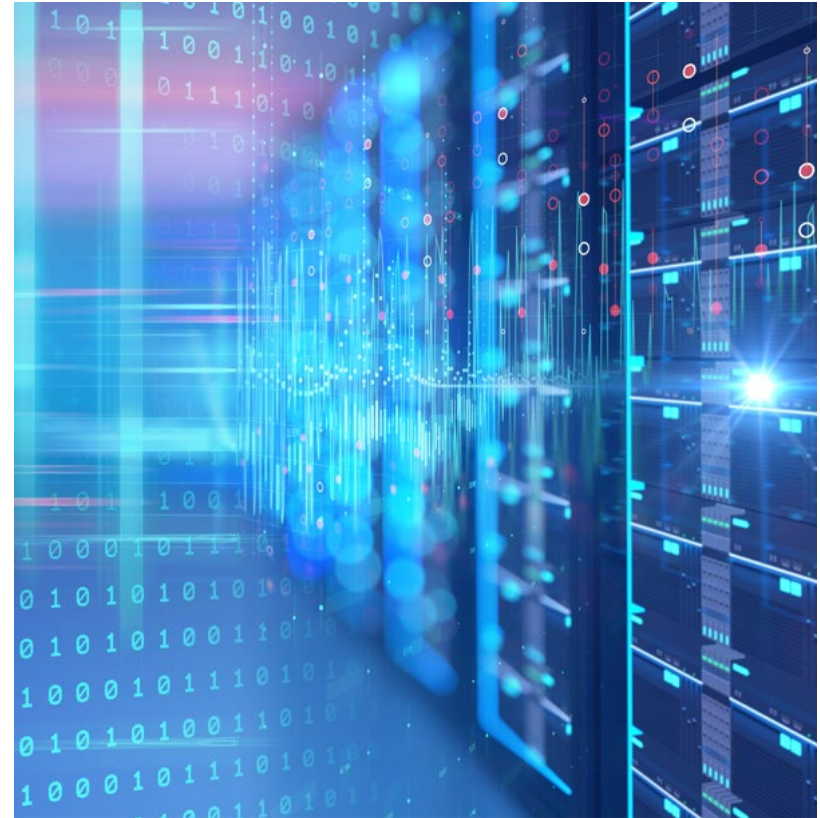
Repositories

Repositories for Sharing Scientific Data

- NIH encourages researchers to select the repository that is most appropriate for their data type and discipline.

Three main repository types:

- Discipline/Subject-Specific
- Generalist
- Institutional



<https://datascience.cancer.gov/news-events/blog/breaking-down-barriers-sharing-cancer-data-nih-generalist-repository-ecosystem>

I. Discipline-Specific Repositories

Discipline-Specific Data Repository

- **Discipline-Specific (or subject) repository** - a repository that contains data pertaining to a specific subject area.
- NIH Strongly recommends using an open, discipline-specific repository as a **first choice** whenever possible.
- Researchers should use the designated data repositories determined by NIH programs, NIH ICOs, or FOAs.
- For data generated from research for which no data repository is specified, researchers should select a data repository that is appropriate for the data generated from the research project.

NIH Supported Discipline-Specific Repositories

NIH Institute, Center, or Office Data Sharing Policies

Institute or Center	Data Sharing Policy Name	Description of Data Sharing Policy	Repositories
HEAL	HEAL Public Access and Data Sharing	Through the NIH HEAL Initiative Public Access and Data Sharing Policy (the Policy), NIH seeks to create an infrastructure that addresses the need for researchers, clinicians, and patients to collaborate on sharing their collective data and knowledge about opioid misuse and pain to provide scientific solutions to the opioid crisis. Under the Policy, applicants for extramural research funding (grants, cooperative agreements, contracts, and other transactions; "Applicants") for NIH HEAL Initiative Research Projects are required to submit a Public Access and Data Sharing Plan that (1) describes their proposed process for making resulting Publications and, to the extent possible, the Underlying Primary Data immediately and broadly available to the public or (2), if applicable, provides a justification to NIH if such sharing is not possible. Underlying Primary Data should be made as widely and freely available as possible while safeguarding the privacy of participants and protecting confidential and proprietary data.	Various HEAL-Compliant repositories
NCI	Cancer Moonshot™ Public Access and Data Sharing Policy	The primary goal of NCI's Cancer Moonshot™ is to significantly accelerate cancer research discovery and meaningful implementation. The Cancer Moonshot Public Access and Data Sharing Policy addresses the recommendation of the Blue Ribbon Panel's Enhanced Data Sharing working group to the National Cancer Advisory Board that researchers, clinicians, and patients should collaborate in sharing their collective data and knowledge about cancer to accelerate progress towards improving cancer outcomes. Under this policy, applicants for Cancer Moonshot Research Projects are required to submit a "Public Access and Data Sharing Plan" that describes their proposed process for making, to the extent possible, resulting Publications and the Underlying Primary Data immediately and broadly available to the public. Investigators applying for Cancer Moonshot funds must provide a justification to NCI if such sharing is not possible.	Genomic Data Commons , dbGaP , TCIA
NCI	NCI Clinical Trial Access Policy	NCI believes that the full value of NCI-supported Interventional Clinical Trials can be realized only if the results of clinical trials are published as rapidly as possible. The Clinical Trial Access Policy aims at ensuring public availability of results from NCI-supported clinical trials from all NCI-funded research grants, cooperative agreements, and/or contracts that support covered interventional clinical trials. Review the NCI Clinical Trial Access Policy for expectations of the policy. Final Trial Results are expected to be reported in a publicly accessible manner within twelve (12) months of the Trial's Primary Completion Date regardless of whether the clinical trial was completed as planned or terminated earlier. Accordingly, data from incomplete trials are also expected to be reported within twelve (12) months of the date that the last subject had data collected or was examined even if the Trial does not achieve its primary aim. To comply with the Policy, Final Trial Results may be reported in a publicly accessible manner in various ways, which include but are not limited to: publishing trial results in a peer-reviewed scientific journal, submitting study reports to publicly accessible registries dedicated to the dissemination of clinical trial information (such as ClinicalTrials.gov), or any other formalized reporting format that	Various



NIH Supported Discipline-Specific Repositories

NIH-supported Scientific Data Repositories

- A list of NIH-supported repositories can be found on their data-sharing website.
 - **101 repositories (open and restricted)**
- **Data sharing information provided:**
 - NIH Institute or Center
 - Name of the repository and link to repository homepage
 - Description and general information about the repository
 - Data submission and permissions guidelines
 - Data submission policy information
 - Requirements for accepting data

NIH-supported Scientific Data Repositories*

Institute or Center	Repository Name	Repository Description	Open Data Submission	Data Submission Policy	Open Time Frame for Data Deposit
All		Keyword Filter			
Common Fund	Metabolomics Workbench (MetWB)	The Metabolomics Program's Data Repository and Coordinating Center (DRCC), housed at the San Diego Supercomputer Center (SDSC), University of California, San Diego, has developed the Metabolomics Workbench. MetWB will serve as a national and international repository for metabolomics data and metadata and will provide analysis tools and access to metabolite standards, protocols, tutorials, training, and more.	Yes	How to submit data to MetWB	Yes
Common Fund	Stimulating Peripheral Activity to Relieve Conditions Portal (SPARC)	The SPARC Portal provides interactive access to a growing collection of data, maps, and computational studies that focus on the role of the autonomic nervous system in controlling organ function. These resources are made available to the public with the intent of advancing bioelectronic medicine towards more precise treatment of diseases and conditions.	Yes	How to submit data to SPARC	Yes
NCATS	BioSystics Analytics Platform (BioSystics-AP)	Microphysiology Systems Database, now called the BioSystics Analytics Platform™, captures, manages, analyzes, shares, and computationally models complex data sets from in vitro experimental models, animal studies, and human clinical data, creating actionable knowledge and predicting biological outcomes that optimizes precision medicine, including preclinical trials. Links to internal and external databases provide information on drugs, assays, preclinical and clinical data for model and study design, and to develop computational models. The BioSystics-AP provides a streamlined workflow for selecting in vitro models, implementing studies and capturing data in a central location for efficient review, analyses and computational modeling. The BioSystics-AP facilitates secure data sharing within a lab and organization, with collaborators, government agencies, and the research community.	Yes	How to submit data to BioSystics-AP	Yes
NCATS	National COVID Cohort Collaborative (N3C)	The NCATS National COVID Cohort Collaborative (N3C) Data Enclave contains harmonized clinical, laboratory and diagnostic data derived from the EHRs of more than 12 million people who were tested for COVID-19 or had related symptoms.	Yes	How to submit data to N3C	Yes

<https://sharing.nih.gov/data-management-and-sharing-policy/sharing-scientific-data/repositories-for-sharing-scientific-data>



II. Generalist Repositories

Generalist Data Repositories

- **Generalist Data Repositories** - accept a wide range of data and are freely accessible to the public.
- Designed to be comprehensive and inclusive rather than specialized in a particular area or type of data.
- **Generalist Repository Ecosystem Initiative (GREI)** – goal is to enable better access to and discovery of NIH-funded data among generalist repositories.
- **GREI** is intended to supplement the domain-specific data repositories that are identified as critical components of the NIH biomedical data ecosystem for data sharing.



<https://www.incf.org/blog/nih-launches-generalist-repository-ecosystem-initiative-increase-access-biomedical-data>

GREI Mission

1. To establish a common set of cohesive and consistent capabilities, services, metrics, and social infrastructure across various generalist repositories.
2. To raise general awareness and help researchers to adopt FAIR principles to better share and reuse data.



NIH Supported GREI Repositories

Dataverse Project (<https://dataverse.org/>)



Dryad (<https://datadryad.org/stash>)



Figshare (<https://figshare.com/>)

Mendeley Data (<https://data.mendeley.com/>)



Open Science Framework (<https://osf.io/>)

Vivli (<https://vivli.org/>)



Zenodo (<https://zenodo.org/>)



Where to find more information about GREI Repositories

NIH Office of Data Science and Strategy – a list of past and upcoming webinars on GREI Repositories:

- Generalist Repository Ecosystem Initiative (GREI) Workshop (**Tuesday, January 24, 2023**)
- Best practices for sharing data in a generalist repository: Metadata, data preparation, and reporting (December 2022)
- How to include generalist repositories in your NIH data management and sharing plans (November 2022)
- Meet the GREI Generalist Repositories (October 2022)
- ODSS Announces New Repository Joining GREI (September 2022)
- NIH Office of Data Science Strategy Announces New Initiative to Improve Access to NIH-funded Data (January 2022)



<https://datascience.nih.gov/data-ecosystem/generalist-repository-ecosystem-initiative>



Other Repository Selection Resources







- **Registry of Research Data Repositories**
(www.re3data.org) – a global registry of research data repositories in all scientific disciplines.
- Managed and maintained by the Humboldt University, Berlin, the GFZ German Research Centre for Geosciences, the Karlsruhe Institute of Technology (KIT), and Purdue University.
- Offers a searchable catalog of repositories
 - Search filters include:
 - Keyword or key-term
 - Subject
 - Content-Type
 - Country
 - Disciplines

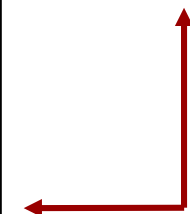


Registry of Research Data Repositories

The screenshot shows the re3data.org website interface. At the top left is the logo 're3data.org'. On the right, there are navigation links: Search, Browse, Suggest, Resources, and Contact. A search bar contains the text 'qualitative data' and a search button. Below the search bar, there are pagination controls showing 'Previous', '1', '2', and 'Next', and a 'Sort by' dropdown menu. A filter sidebar on the left lists various categories like Subjects, Content Types, Countries, etc. The main content area displays three search results:

- eLabour**: Interdisciplinary center for qualitative research data from the sociology of work (eLabour). Subject(s): Social Sciences, Social and Behavioural Sciences, Humanities and Social Sciences. Content type(s): Standard office documents. Country: Germany. Description: A number of sociological research institutions have worked together with partners from IT and the information sciences to establish a new research data infrastructure for qualitative research, the interdisciplinary center for qualitative research data from the sociology of work (eLabour). The infrastructure will be fully operational in early 2019. In addition, the center will expand its qualitative data pool and open up to external scientists. At the same time, IT-based processes and tools for qualitative data management are being developed to establish a competence center for professional qualitative research data management, which can provide support and services for a variety of scientific user groups. Research data are available as Scientific Use Files (SUF) and Campus Files (CF). List of available research data at 'Projects' page: <http://elabour.de/sekundaeranalysen/projekte/>
- Qualitative Data Repository (QDR)**: QDR. Subject(s): Empirical Social Research, Political Science, Social and Behavioural Sciences, Social Sciences, Humanities and Social Sciences, Education Sciences, Jurisprudence, Humanities and Social Sciences, Psychology, History, Public Health, Health Services Research, Social Medicine, Geography, Social and Cultural Anthropology and Ethnology/Folklore, Humanities, Medicine, Medicine, Life Sciences, Geosciences (including Geography), Natural Sciences, Non-European Languages and Cultures, Social and Cultural Anthropology, Jewish Studies and Religious Studies. Content type(s): Audiovisual data, Scientific and statistical data formats, Images, Standard office documents, Raw data, other, Plain text, Structured text. Country: United States. Description: The Qualitative Data Repository (QDR) is a dedicated archive for storing and sharing digital data (and accompanying documentation) generated or collected through qualitative and multi-method research in the social sciences. QDR provides data management consulting services and actively curates all data projects, maintaining the value and usefulness of the data over time, and ensuring their availability and findability for re-use.
- Qualiservice**: Research Data Center Qualiservice. Subject(s): Humanities and Social Sciences, Social and Behavioural Sciences, Non-European Languages and Cultures, Social and Cultural Anthropology, Jewish Studies and Religious Studies, Education Sciences, Psychology, Social Sciences, Social and Cultural Anthropology and Ethnology/Folklore, Empirical Social Research, Communication Science, Political Science.

-  Additional info.
-  Restricted access
-  Licenses
-  DOI
-  Certifications
-  Policies



Other Data Sharing Resources

- Nature's Data Repository Guidance Website

[https://www.nature.com/sdata/policies/repositories#:~:text=Data%20repositories%20should%20meet%20all,submitted%20datasets%20\(e.g.%20Datacite%20DOIs\)](https://www.nature.com/sdata/policies/repositories#:~:text=Data%20repositories%20should%20meet%20all,submitted%20datasets%20(e.g.%20Datacite%20DOIs))

The logo for Nature, featuring the word "nature" in a black, serif font on a light grey rectangular background.

- FAIRsharing registry (<https://fairsharing.org/>)

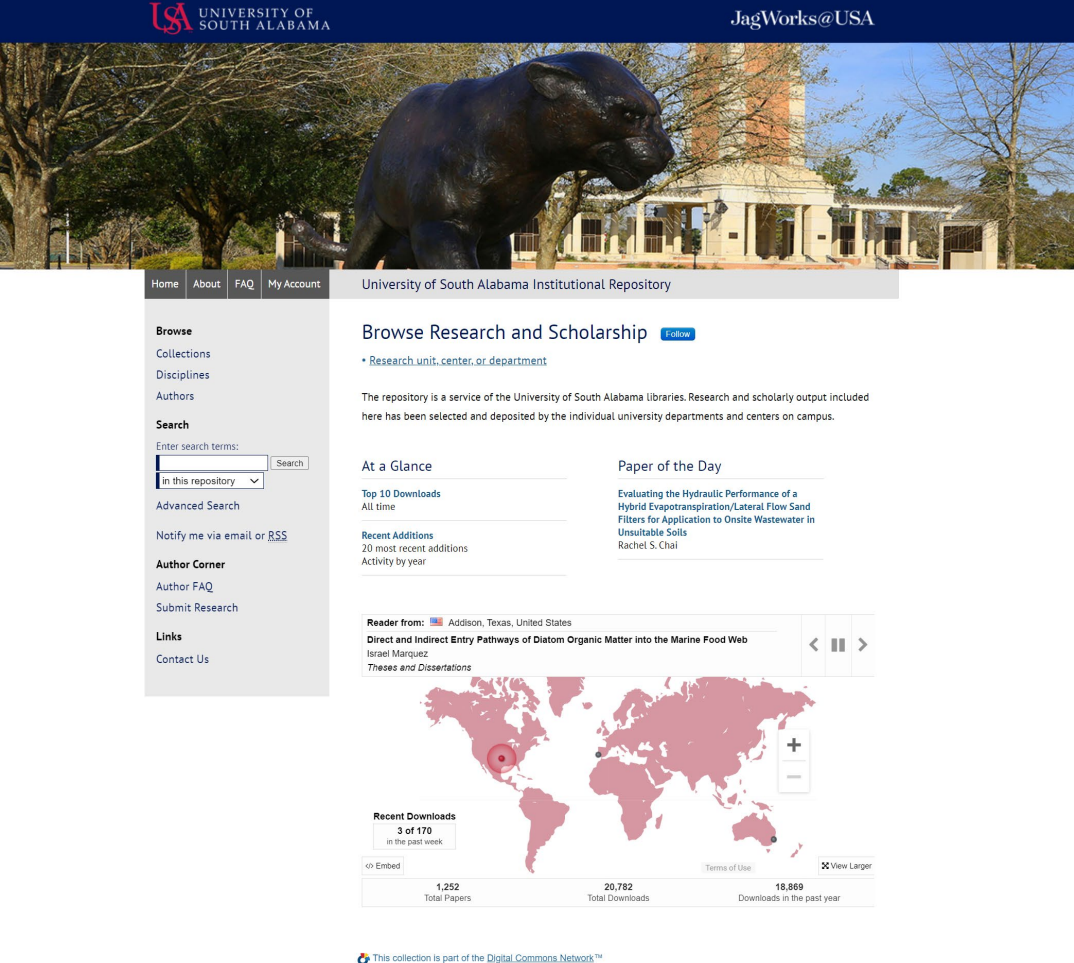


III. Institutional Repository

JagWorks – USA’s Institutional Repository

JagWorks@USA Repository – open access, digital archive provided by the USA Libraries (<https://jagworks.southalabama.edu>)

- Submitted content is immediately searchable
 - **Google and Google Scholar**
- Available for use by anyone affiliated with USA or USA Health Services
 - Faculty
 - Researchers
 - Staff
 - Students (with approval)
- JagWorks meets NIH desirable characteristics of data repositories



UNIVERSITY OF SOUTH ALABAMA JagWorks@USA

University of South Alabama Institutional Repository

Browse Research and Scholarship [Follow](#)

• [Research unit, center, or department](#)

The repository is a service of the University of South Alabama libraries. Research and scholarly output included here has been selected and deposited by the individual university departments and centers on campus.

At a Glance

Top 10 Downloads
All time

Recent Additions
20 most recent additions
Activity by year

Paper of the Day

Evaluating the Hydraulic Performance of a Hybrid Evapotranspiration/Lateral Flow Sand Filters for Application to Onsite Wastewater in Unsuitable Soils
Rachel S. Chai

Reader from: Addison, Texas, United States

Direct and Indirect Entry Pathways of Diatom Organic Matter into the Marine Food Web
Israel Marquez
[Theses and Dissertations](#)

Recent Downloads
3 of 170
in the past week

1,252	20,782	18,869
Total Papers	Total Downloads	Downloads in the past year

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What can be submitted to JagWorks?

❖ 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
 - ✓ Textbooks
 - ✓ Training materials/SOPs

❖ Accommodates most common file types

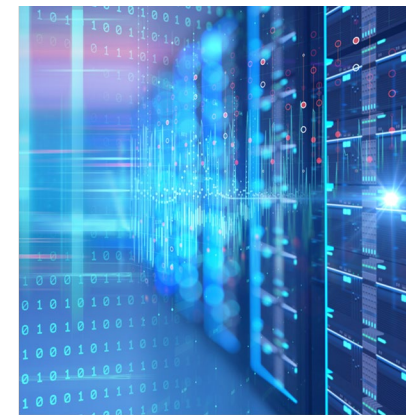
- **Examples:** (not an exhaustive list)
 - .doc/.docx
 - .mp3/.mp4
 - .xls/.xlsx
 - .jpg/.jpeg/.jpx
 - .pdf
 - .tiff
 - .gif
 - .png
 - .bmp
 - .eps
 - .rtf
 - .zip

JagWorks Tools and Services

- Real-time usage metrics and readership impact with PlumX Analytics
- Unlimited storage and access with no size limits on content
- Peer review tools for most publication types
- **Unique persistent identifiers (URLs)**
- **Access controls and embargos for sensitive or restricted content**
- **Customizable metadata fields**
- Closed-captioning for video and audio files
- Assistance with content design, layout, and formatting
- In-house management of all content in JagWorks



<https://www.iec.ch/blog/important-role-access-control-cyber-security>



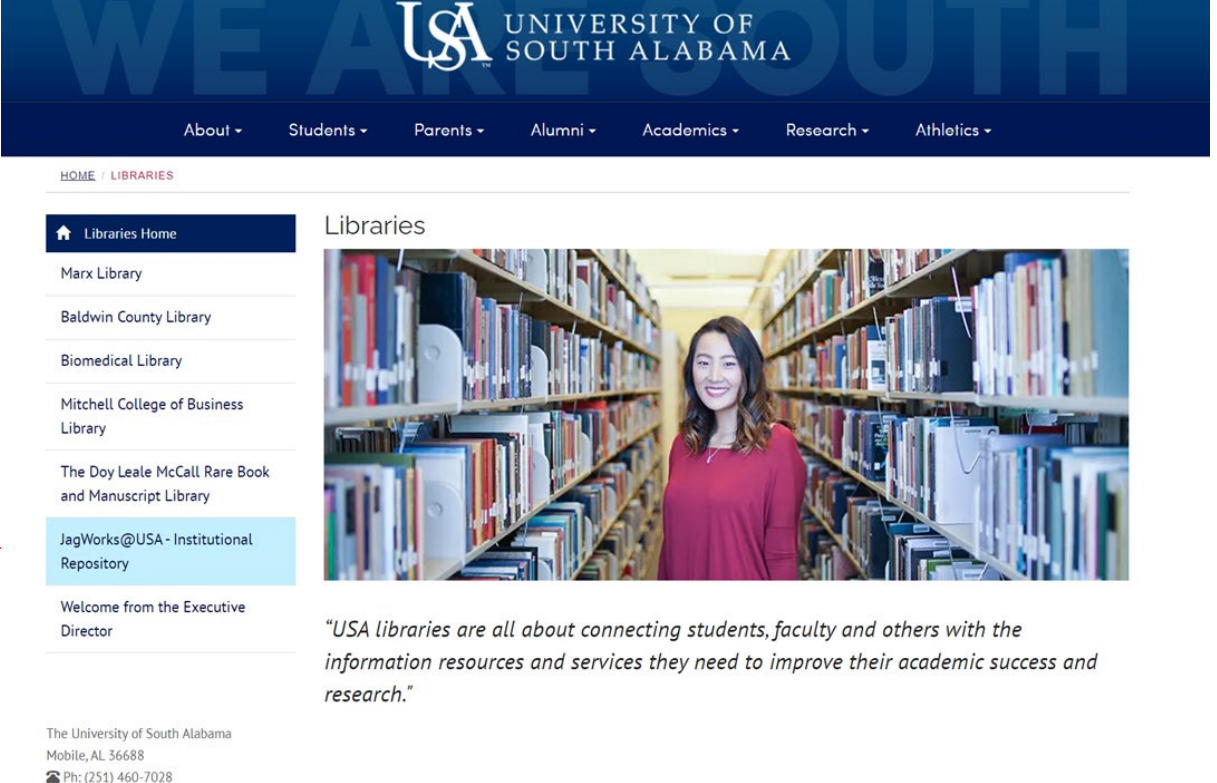
<https://data.science.cancer.gov/news-events/blog/breaking-down-barriers-sharing-cancer-data-nih-generates-repository-ecosystem>



Where to find JagWorks@USA?

You can find JagWorks at:

- www.jagworks.southalabama.edu
- Contact me, Jana Herrmann
 - Email – jherrmann@southalabama.edu
 - JW email – jagworks@southalabama.edu
- Click on the link on the USA Libraries home page.
- ‘Contact Us’ link on JagWorks homepage



The screenshot shows the top navigation bar of the USA Libraries website with the University of South Alabama logo and the text "WE ARE SOUTH". Below the navigation bar is a list of libraries: Marx Library, Baldwin County Library, Biomedical Library, Mitchell College of Business Library, The Doy Leale McCall Rare Book and Manuscript Library, and JagWorks@USA - Institutional Repository. A red arrow points to the "JagWorks@USA - Institutional Repository" link. To the right of the list is a photo of a woman in a red shirt standing in a library aisle. Below the photo is a quote: "USA libraries are all about connecting students, faculty and others with the information resources and services they need to improve their academic success and research."

Where to find JagWorks@USA?

Research Data Management Biomedical Library Subject Guide - Data Repositories

Managing Research Data from Start to Finish: Data Repositories

This subject guide provides information on how to manage research data.

Home | Data Management Plans | DMPTool | **Data Repositories** | Budgeting | Human Data | Data Capture with REDCap | Training Videos for the USA Community

Contact Information

Data Repository Search

- **Re3data: Registry of Research Data Repositories**
Searchable, browsable tool for identifying repositories
- **DataCite**
DataCite gathers metadata for each DOI assigned to an object. The metadata is used for a large index of research data that can be queried directly to find data, obtain stats and explore connections. All the metadata is free to access and review.
- **OAD Data Repositories List**
Annotated List organized by subject
- **NIH Data Sharing Repositories**
Listing of NIH-supported repositories

Biomedical & Life Sciences Repositories

- **DataMed**
DataMed is a prototype biomedical data search engine that searches through bioCADDIE. Its goal is to discover data sets across data repositories or data aggregators.
- **NIH Open Domain-Specific Data Sharing Repositories**
This table lists NIH-supported domain-specific data repositories that make data accessible for reuse and are open for both submitting and accessing data. Submission is typically limited to data of a certain type or related to a certain discipline. The table provides links to information about submitting data to and accessing data from the listed repositories. Repositories in this list have current NIH funding, sustained support, open data submission and access, and open time frame for data deposit, based on information provided by the repository about funding and data availability. This non-exhaustive list is also available in a [downloadable Excel version](#).
- **Other NIH Data Resources**
This table lists NIH-supported domain-specific data resources that do not meet the full criteria for inclusion on the [Open Repositories list](#). This list includes repositories that restrict data submission to a specific set of researchers, as well as those that limit who may access

University of South Alabama Institutional Repository

- **JagWorks@USA**
This repository is a service of the University of South Alabama libraries. Research and scholarly output included here has been selected and deposited by the individual university departments and centers on campus.

Submitting Content to JagWorks
To submit content to JagWorks, please contact Jana Herrmann at jherrmann@southalabama.edu or email your request to jagworks@southalabama.edu. In the request, please include your name, department, university affiliation/designation (e.g., faculty, staff, student, etc.), contact information, and a brief description of the material to submit. A submission request can also be made through the "Contact Us" link on the JagWorks@USA homepage (<https://jagworks.southalabama.edu/>).

General Data Repositories

- **Dryad**
Repository supporting a wide variety of scientific and medical research data associated with published articles
- **figshare**
Repository supporting all file formats for widely sharing

The TRUST Principles for Digital Repositories

Transparency, Responsibility, User focus, Sustainability and Technology: the TRUST Principles provide a common framework to facilitate discussion and implementation of best practice in digital preservation by all stakeholders.



Other Data Sharing Options

Other Data Sharing Resources

- **Cloud-Based Storage**

- Large datasets (petabytes-scale)

- **NIH STRIDES Initiative**

(Science and Technology Research Infrastructure for Discovery, Experimentation, and Sustainability)

- Allows NIH to explore the use of cloud environments to streamline NIH data use by partnering with commercial providers.

- Google Cloud
- Amazon Web Services
- Microsoft Azure



Google Cloud



- **PubMed Central**

- Stores publication-related supplemental materials and datasets directly associated with publications.
- Datasets ≤ 2 GB



<https://www.ncbi.nlm.nih.gov/pmc/>

Genomic Data Sharing

Genomic Data Sharing (GDS) Policy Overview

Develop and Submit DMS Plan

- Single plan that address GDS and DMS policies

•Provide Institutional Certification form

- Only for Human Data

•Submit genomic data to appropriate repository

•Responsibly use controlled-access data

Cite controlled-access data appropriately in publications and presentations

<https://sharing.nih.gov/genomic-data-sharing-policy/about-genomic-data-sharing>

Considerations for Submitting Genomic Data

- Data submission expectations are dependent on the type of data (human/non-human) and level of processing.
- All studies generating human genomic data must register in the **Database of Genotypes and Phenotypes (dbGaP)** - even if the data will be submitted elsewhere.
- Must ensure all data security measures for human participant data are in place if submitting data to an outside NIH repository.
- Must ensure that data confidentiality, privacy, and usage measures follow GDS policy if submitting data to outside NIH repository.
- **Non-NIH-funded** researchers and institutions submitting data to dbGaP should seek a **Certificate of Confidentiality**.
- When choosing a repository, be sure to check for FOA and IC-specific requirements.
- Non-human genomic data can be submitted to any widely used repository.

Where to Submit Human Genomic Data

Frequently Used Repositories for Human Genomic Data (18 repositories listed)

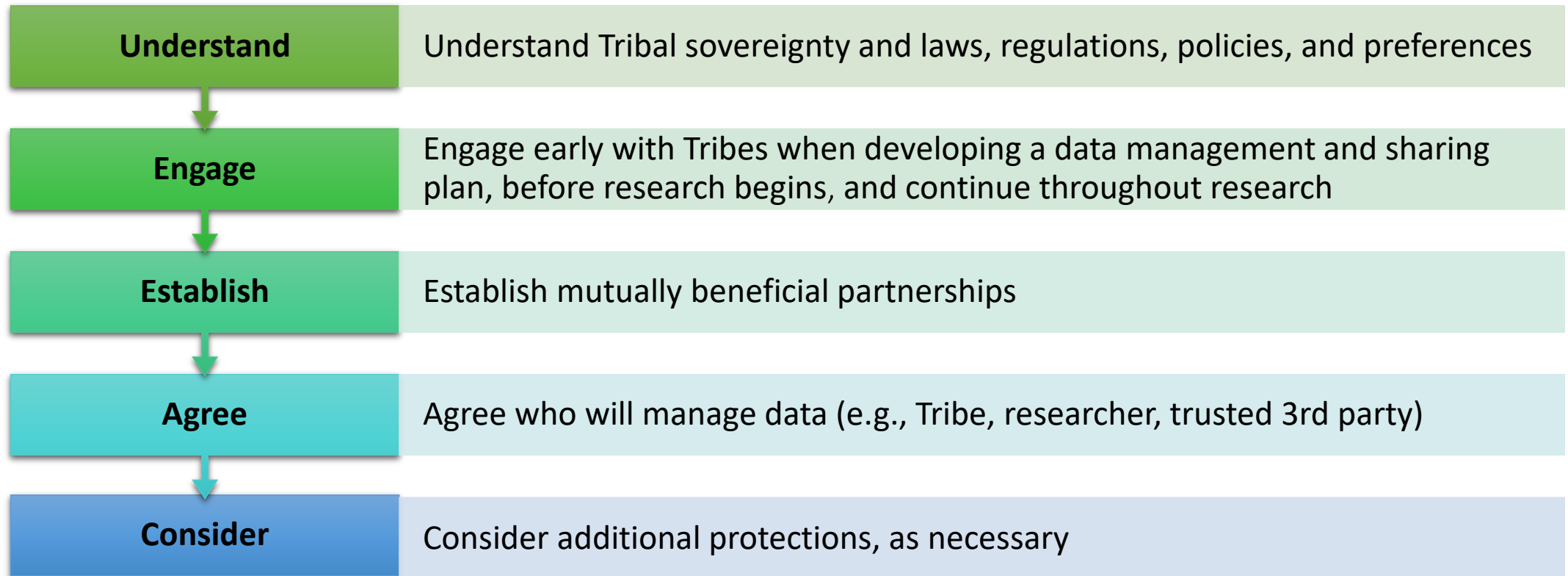
Repository	Repository Description	Submission Guides & Portals
AnVIL	The NHGRI Genomic Data Science Analysis, Visualization, and Informatics Lab-Space, or AnVIL, provides a cloud environment for the analysis of large genomic and related datasets.	AnVIL Data Portal
ArrayExpress	The ArrayExpress Archive of Functional Genomics Data stores data from high-throughput functional genomics experiments, and provides these data for reuse to the research community.	ArrayExpress submission
BioData Catalyst	NHLBI BioData Catalyst is a cloud-based platform providing tools, applications, and workflows in secure workspaces.	Accessing BioData Catalyst Data

Where to Submit Non-Human Genomic Data

Frequently Used Repositories for Non-Human Genomic Data (13 repositories listed)

Repository	Repository Description	Submission Portal
ArrayExpress	The ArrayExpress Archive of Functional Genomics Data stores data from high-throughput functional genomics experiments, and provides these data for reuse to the research community.	ArrayExpress submission portal
DNA Data Bank of Japan (DDBJ)	DDBJ provides freely available nucleotide sequence data and supercomputer system, to support research activities in life science.	DDBJ submission portal
European Nucleotide Archive (ENA)	ENA is an open, supported platform for the management, sharing, integration, archiving and dissemination of sequence data.	ENA submission portal
FlyBase	FlyBase is a database of <i>Drosophila</i> genes and genomes.	FlyBase

Best Practices for Responsible Management and Sharing of AI/AN Participant Data



National Institutes of Health (2022). *Implementing the NIH Data Management and Sharing (DMS) Policy* [PowerPoint Slides].

Supplemental Information NOT-OD-22-214 (<https://grants.nih.gov/grants/guide/notice-files/NOT-OD-22-214.html>)

Resources

For more information and questions?

NIH Data Management and Sharing Policy website:

<https://sharing.nih.gov/data-management-and-sharing-policy>

NIH DMS FAQs:

<https://sharing.nih.gov/faqs#/data-management-and-sharing-policy.htm>

NIH Genomic Data Sharing Policy website:

<https://sharing.nih.gov/genomic-data-sharing-policy>

Managing Research Data from Start to Finish subject guide:

https://libguides.southalabama.edu/research_data_mgt

If you have questions or would like a consultation regarding your DMS planning process, please contact the appropriate person:

Data Management & Sharing Plan Development:

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DMPTool:

Dusty Layton (dlayton@southalabama.edu)

JagWorks Institutional Repository:

Jana Herrmann (jherrmann@southalabama.edu)

NIH Data Management & Sharing Policies:

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