Evolution of the Biomedical Data Repository Ecosystem

the role of generalist repositories

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GREI Workshop Panel on NIH Stakeholder Perspectives
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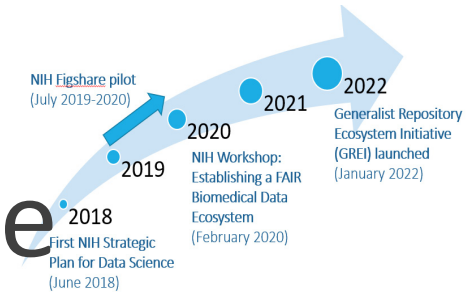
Timeline of NIH Generalist Repository Activities

2018 NIH Strategic Plan for Data Science



Data Infrastructure

- Optimize data storage and security
- Connect NIH data systems

Modernized Data Ecosystem

- Modernize data repository ecosystems
- Support storage and sharing of individual datasets
- Better integrate observational and clinical data into biomed data science

Data Management, Analytics & Tools

- Support useful, generalizable, and accessible tools
- Broaden utility of, and access to, specialized tools
- Improve discovery and cataloging resources

Workforce Development

- Enhance the NIH data science workforce
- Expand the national research workforce
- Engage a broader community

Stewardship and Sustainability

- Develop policies for a FAIR data ecosystem
- Enhance stewardship

2018 Guidance: Repositories for Biomedical Data Sharing

NIH encourages researchers to share data using DOMAIN-SPECIFIC REPOSITORIES when available.

When domain-specific data repositories are not available, NIH is developing options to support data sharing.

Datasets up to **2 gigabytes**

PubMed Central

- PMC stores publication-related supplemental materials and datasets directly associated publications. Up to 2 GB.
- Generate Unique Identifiers for the stored supplementary materials and datasets.

Datasets up to **20*gigabytes**

Use of commercial and non-profit repositories

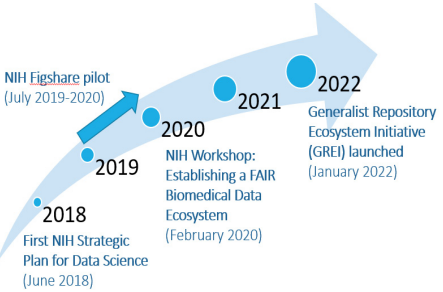
- Assign Unique Identifiers to datasets associated with publications and link to PubMed.
- Store and manage datasets associated with publication, up to 20* GB.

High Priority Datasets **petabytes**

STRIDES Cloud Partners

- Store and manage large scale, high priority NIH datasets. (Partnership with STRIDES)
- Assign Unique Identifiers, implement authentication, authorization and access control.

Data Archipelago, not a Landscape



NIH needed to:

- Find additional data sharing solutions to build out the data ecosystem
- Understand the potential role of the rapidly growing Generalist Repositories

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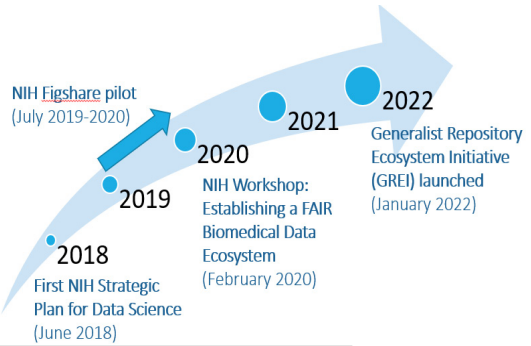
Established a one-year pilot to investigate the potential of Generalist Repositories

Opportunities: Generalist Repositories & NIH



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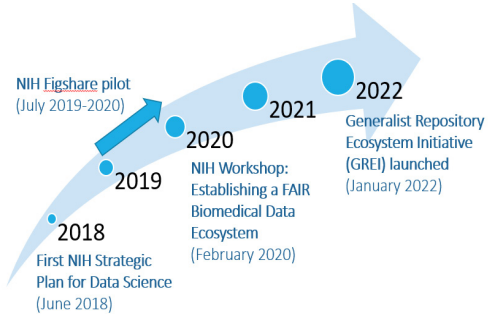
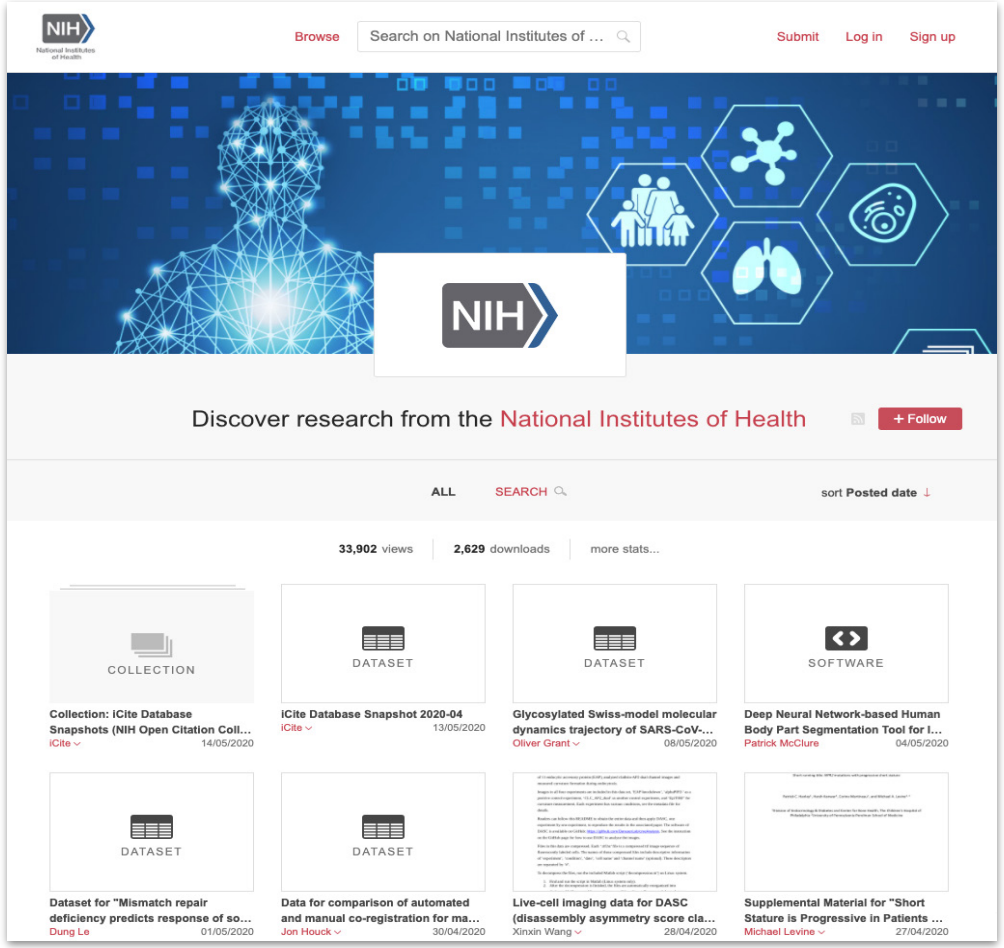
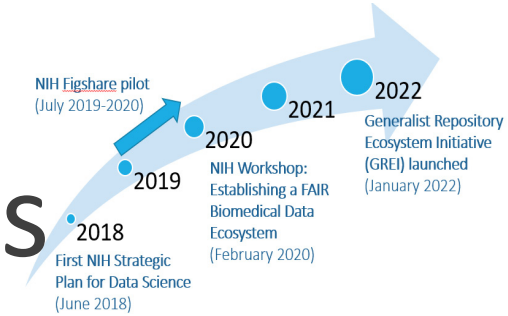
2019 Figshare Pilot



- **Pilot a data sharing platform** to enable NIH funded researchers to easily share data that was generated from NIH support.
- For research that **did not have an alternative venue** through which to share publication-related data.
- Enable the NIH to **better understand the patterns of data sharing by the researchers** it funds.
- Allowed storage of **datasets, spreadsheets, multimedia**, but NOT posters, slides or preprints.
- Increased funding **metadata and QC support**.

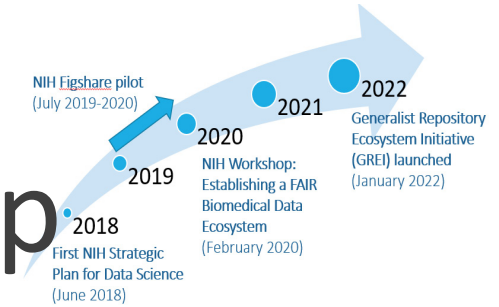


NIH Figshare Pilot – Key Takeaways



- **Generalist repositories are growing –** more researchers are depositing data and more publications are linking to generalist repositories.
- **Researchers need more education and guidance –** where to publish data and how to describe datasets in metadata fields effectively.
- **Metadata enhancement enables greater discoverability –** metrics indicate greater access but need longer time scale to observe data reuse.
- **There is a clear need for the services that repositories like Figshare provide –** researchers have data (and other materials) that they want to share but there are not suitable repositories.

2020 Generalist Repository Workshop



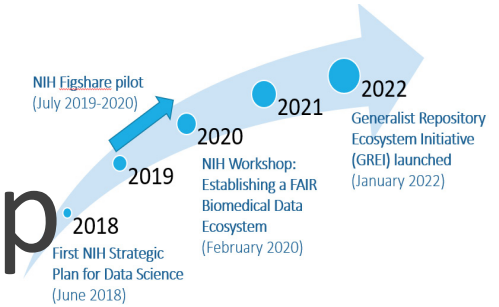
- **Establishing a FAIR Biomedical Data Ecosystem: Role of Generalist and Institutional Repositories to Enhance Data Discoverability and Reuse** (February 2020)
- Highlighted the breadth and depth of activities of generalist and institutional repositories in supporting biomedical researchers and biomedical data

Day 1: A Landscape of Generalist Repositories and Challenges in Data Discovery and Reuse

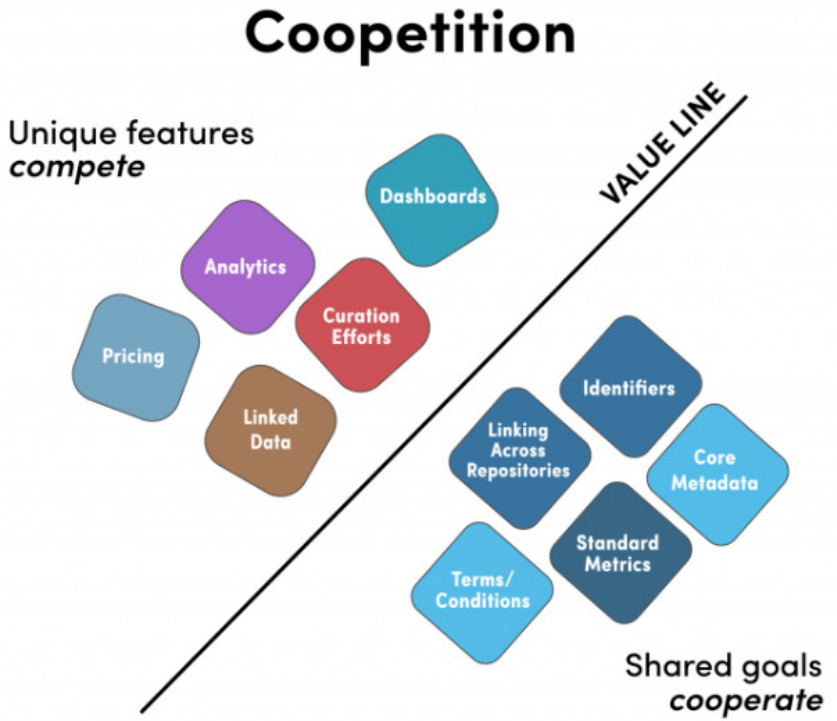
Day 2: Facilitating Reproducibility and Managing Technical and Cultural Change in Research

https://datascience.nih.gov/data-ecosystem/nih-data-repository-workshop-summary

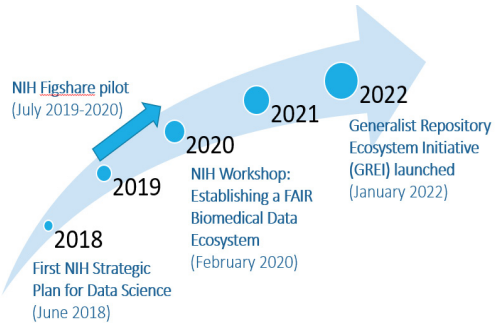
2020 Generalist Repository Workshop



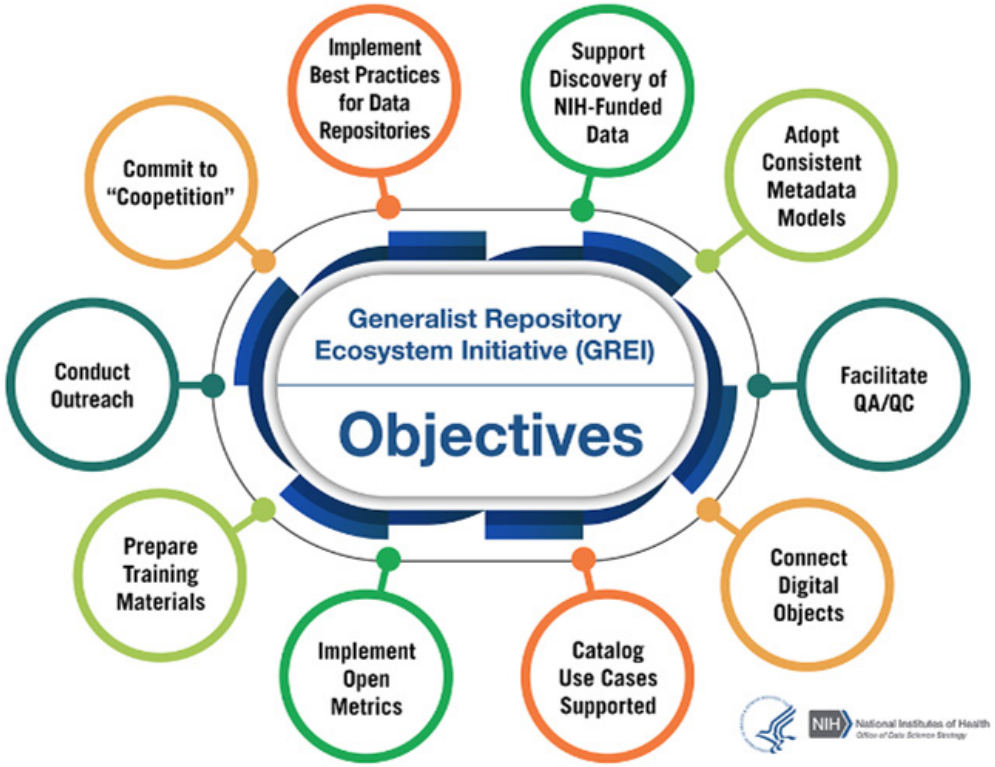
- **Coopetition**: A vibrant repository community includes participants in industry, academia, and government
- **Value line** to determines where to compete on services and when to collaborate.
- Following the workshop, generalist repositories worked together to develop a summary of repository capabilities to establish the **"coopetition" framework**.



2022: Generalist Repository Ecosystem Initiative (GREI)



- GREI is intended to **supplement the domain-specific data repositories** that are critical components of the NIH biomedical data ecosystem for data sharing.
- GREI repositories are identifying and implementing **collaborative activities**: shared metadata for improved discoverability, inclusion of funding and grant information, etc.
- GREI aims to make it easier to find and reuse NIH-funded data.



NIA & Generalist Repositories

Who is NIA?

- NIA is the third largest NIH Institute ($4.4B in FY23)
- Supports a **broad range of science**: the breadth of science from across NIH: basic (molecular cellular and genetic), clinical, behavioral, epidemiological, and therapeutics.
  - NIA leads a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life.
  - Dedicated funding to support research on NIA Alzheimer's Disease (AD) and related dementias (ADRD).
- In addition to NIA's Intramural Research Program in Bethesda and Baltimore. NIA and NINDS support NIH Intramural **Center for Alzheimer's and Related Dementias** (CARD).
  - CARD seeks to advance AD/ADRD research through a data-driven and collaborative approach that emphasizes robust, replicable findings and cooperative progress over individual success.

Challenges to NIA Data Sharing

- Diversity of NIA research makes it challenging to also identify and support domain-specific repositories.
- NIA-supported data repositories and knowledgebases: https://www.nia.nih.gov/research/data-sharing-resources-researchers

AgingResearch Biobank

PAD

NIDUS Network for Investigation of Delirium: Unifying Scientists

AD Knowledge Portal

NACDA National Archive of Computerized Data on Aging

NIAGADS

Challenges to NIA Data Sharing

- NIA encourages the use of domain-specific repositories (supported by NIA, where possible, otherwise other repositories that align with the Key Characteristics).
- But Generalist Repositories will play an important role to:
  - Provide a FAIR repository when no specialized repositories exist
  - Facilitate in connecting datasets across multiple repositories, for projects that generate diverse data types.
- As DMS Policy gets implemented, we anticipate **increased use of all repositories** (including GREI) and **improved and more consistent metadata** at all repositories to support easier discovery and access … to realize the FAIR biomedical data ecosystem.
- Future Challenge: ensuring that NIA-supported data is not only Findable and Accessible but is also truly **Interoperable and Reusable**!

Thank you!

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