

Data Resources, Sustainability and NIH

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Role of Data Science at NIH

FAIR

Enable broad data sharing and reuse of data Findable, Accessible, Interoperable, and Re-usable (FAIR)

Commons

Support biomedical discovery by enabling the sharing of digital objects

Training

Enable an effective and diverse biomedical, data science workforce

Sustainability

Develop an NIH vision for economic, technical, and social stewardship of biomedical data repositories.





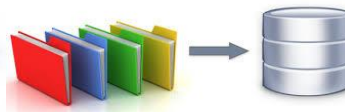
BD2K Investments

BD2K larger Centers & related Activities

Workforce

Targeted Software

Sustainability



- *Metadata tools and standards*
- *APIs for mapping, sharing, & integrating heterogeneous data*

- *Open Educational Resources on data science*
- *Open Educational Resources on research data management*

- *Data Provenance & Data Wrangling, Data Privacy*

- *Inventory of NIH Data Repositories and Costs*
- *NIH Commons*
- *Interoperability projects*
- *Sustainability FOAs*
- *Policy*

Recommendations



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Current Ecosystem of Biomedical Research Data Resources

**NIH Extramural
Researcher(s)**



**US Scientific
Repositories**



Other Agencies



NIH Intramural IC-based



Archival – NLM



**International
Repositories**



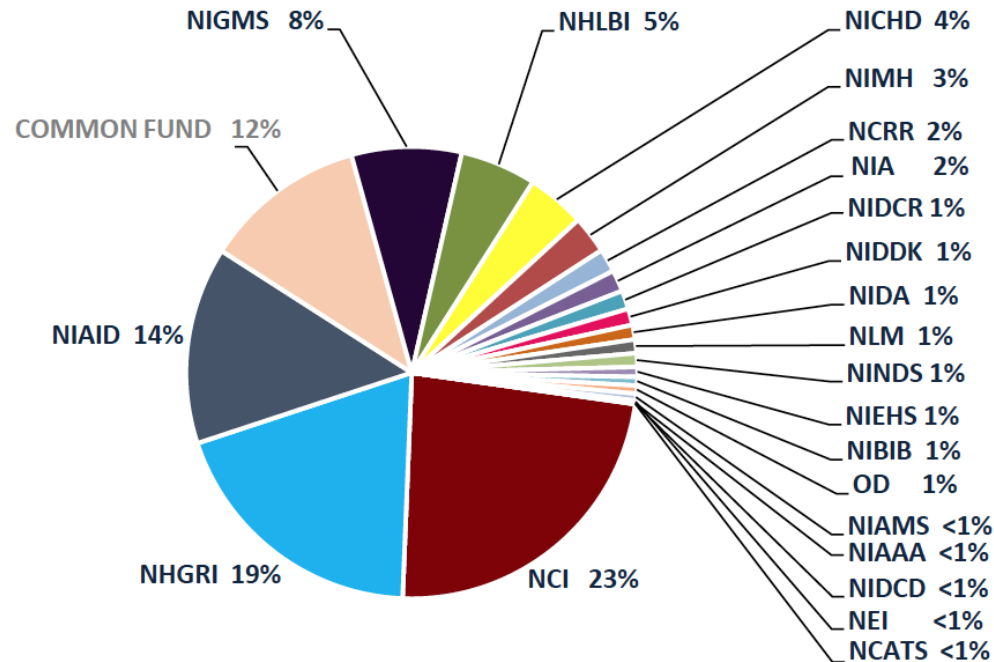
Standards, data formats, accessibility, utility, completeness vary



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Estimated Extramural Data Repository Spending Across NIH FY2007-FY2014, Gross Totals*



Number of Extramural Data Repositories Sampled

Gross Total Spent (Unadjusted)

Gross Total Spent (Inflation-Adjusted)

131

\$1.34 Billion

\$1.27 Billion (2014 USD)

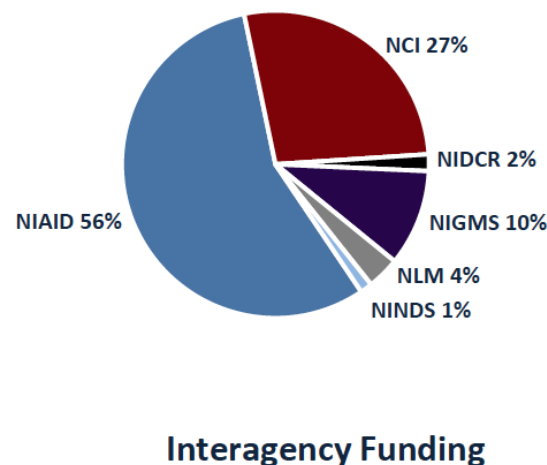
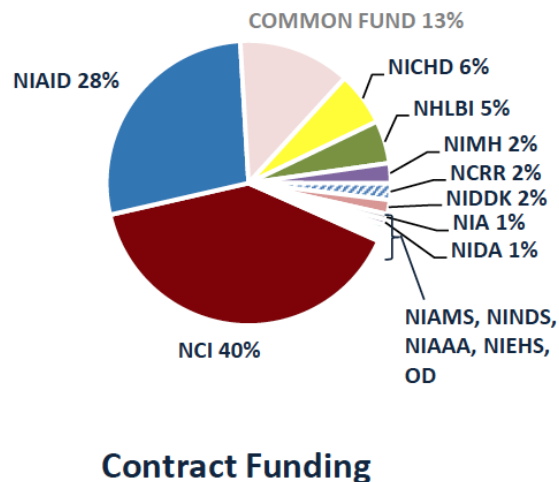
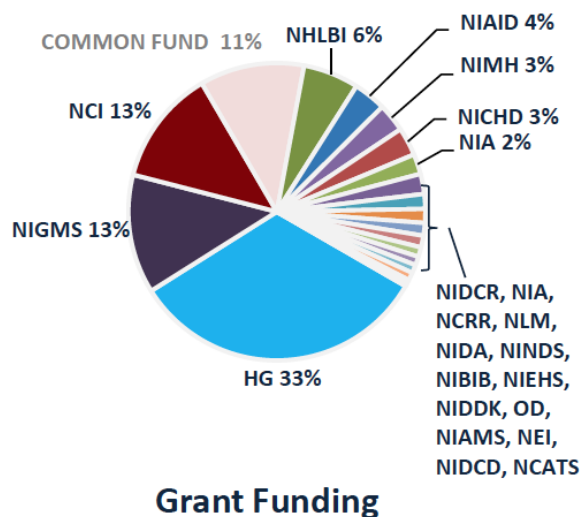
*Please note that some repositories are funded in a hybrid scheme involving multiple institutes or funding mechanisms, which confounds subtotals. Sample data last updated 10-2016.



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Estimated Extramural Data Repository Spending Across NIH FY2007-FY2014, by Funding Type*



86 Repositories
(Approx. 65% of Sample)

Gross Total Spent (Inflation-Adjusted)
>\$795 Million (2014 USD)

41 Repositories
(Approx. 31% of Sample)

Gross Total Spent (Inflation-Adjusted)
>\$487 Million (2014 USD)

8 Repositories
(Approx. 6% of Sample)

Gross Total Spent (Inflation-Adjusted)
>\$30 Million (2014 USD)

*Please note that some repositories are funded in a hybrid scheme involving multiple institutes or funding mechanisms, which confounds subtotals. Sample data last updated 10-2016.





Sustainability at NIH

Function

Develop an NIH vision for economic, technical, and social stewardship of biomedical data repositories.

Goals

Goal 1: Define Metrics for Evaluation of Biomedical Data Repositories and Assess Value.

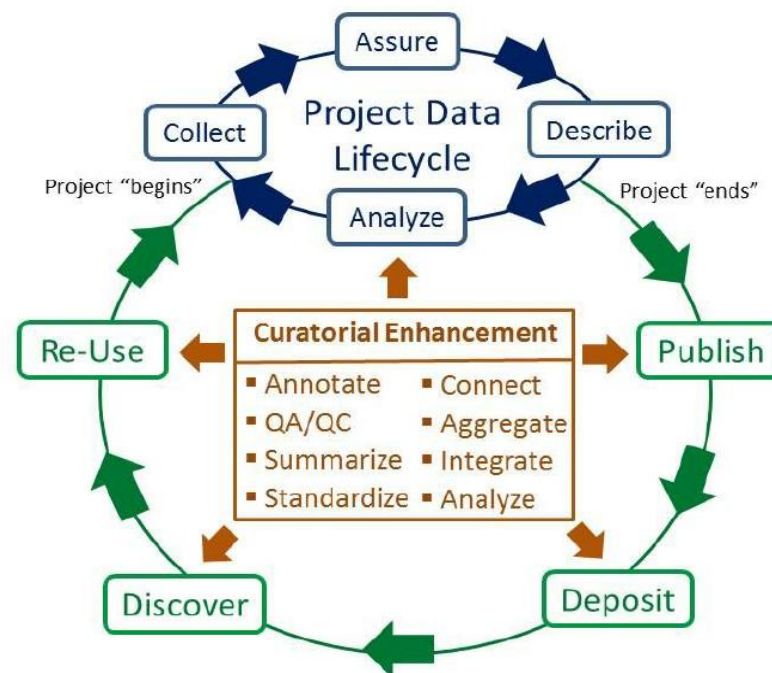
Goal 2: Develop a Sustainable Lifecycle and Coherent Funding Plan in support of Biomedical Research Data.





Funding Opportunity Announcement (FOA): Improving Efficiencies and Innovations in Curation

- Tools to facilitate the use of community data standards
- Automated or semi-automated approaches
- Improve speed and accuracy and harmonization
- Support data annotation at points throughout the research lifecycle



Distributed, Crowdsourced
approaches to curation



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Other solutions explored

- Request For Information (RFI): Metrics to Assess Value of Biomedical Digital Repositories
 - Responses mainly from US and UK academic stakeholders (98 total)
- Recommendations for NIH repository support
 - Mechanism(s), review criteria, implementation
- International collaboration on business and funding models
- Pilots: MODs reorganization and the Commons





Sustainability WG Members

- Vivien Bonazzi, OD
- Allen Dearry, NIEHS
- Valentina Di Francesco, NHGRI
- Valerie Florance, NLM
- Susan Gregurick, NIGMS
- Izumi Hinkson, OD
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- Kim Pruitt, NCBI
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