Data Sharing
Nonprofit Nongovernmental Funders’ Perspective

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Health Research Alliance Mission

HRA, a collaborative member organization of nonprofit research funders, is committed to maximizing the impact of biomedical research to improve human health.
Who are HRA’s 80 Members?

2/3 Public Charities
1/3 Private Foundations

Annual Grant Budgets

Less than $5 M | $5 M - $9.9 M | $10 M - $19.9 M | $20 M - $39.9 M | $40 M - $59.9 M | $60 M - $79.9 M | $80 M or more
Clinical Trials: Candidate Alzheimer’s Disease Compounds (2002-2012)

413 Total Clinical Trials (clinicaltrials.gov)
  124  Phase I
  206  Phase 2
  83   Phase 3

244 Compounds Tested
  72%  Failure Rate  Phase 1
  92%  Failure Rate  Phase 2
  98%  Failure Rate  Phase 3

244 compounds tested only ONE was approved for marketing

99.6% FAILURE IS UNACCEPTABLE


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2/3 of Studies in 67 Projects Not Reproducible

From Bayer Healthcare: Nature Reviews Drug Discovery 10, 712 (September 2011)
doi:10.1038/nrd3439-c1
Open, Transparent, Rigorous Science Accelerates Research and Improves Human Health

Require Open Access to publications
Encourage use of interim research products (preprints, preregistration)
Require collaboration with biostatisticians
Require data management plans
Require collaboration with data stewards
Require awardees “share their data” (What does that mean?)
From Hand Wringing to Taking Action

• Created an Open Science Task Force
• Task Force Developed a Topic List
• Found Partners
• Learn from others – webinars/workshops
OSTF’s “To-Do” List

• Create infrastructure to comply with NIH’s Public Access Policy (PMC part of HRA OPEN)
• Create infrastructure to enable Open Data (Figshare part of HRA OPEN)
• Incentivize awardees to share data - linked to grant
• Develop best practices in data sharing
• Create guidance for choosing an appropriate trusted repositories
• Create template data sharing policies (modular)
• Implement data sharing policies
• Share polices and experiences – what worked and why?
Please select the funder associated with your research data
OSTF’s “To-Do” List

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What is Data Sharing?

Intro to Data Sharing Webinar:
  What do we mean by sharing?
  What do we mean by data?

Perspectives from:
  PLOS ONE
  Natures’ Scientific Data

Topics:
  FAIR Principles
  Trusted Repositories
  Data Availability Statements
## Implementing Data Sharing

### Recommended Data Repositories

<table>
<thead>
<tr>
<th>Harvard Dataverse</th>
<th>Contact repository for datasets over 1 TB</th>
<th>2.5 GB per file, 10 GB per dataset</th>
<th>No</th>
<th>view re3data entry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open Science Framework</td>
<td>Free of charge</td>
<td>5 GB per file, multiple files can be uploaded</td>
<td>No</td>
<td>view FAIRsharing entry</td>
</tr>
</tbody>
</table>

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An overly simple guide to picking the right data repository

https://www.nature.com/sdata/policies/repositories

Does your dataset contain sensitive information derived from human participants?
- No
- Yes

Is there a repository on our list specializing in your data-type? e.g. GenBank for sequences
- No
- Yes

Does your institution have its own data repository?
- No
- Select a generalist repository from our list
- Yes

Use it!

Do consent agreements and ethical/legal requirements permit sharing of data with qualified outside researchers?
- Yes
- No

Select an appropriate restricted-access repository
- Use it!

Publicly expose the data use agreement and application process

Seek further advice

A. L. Hutton MRA 2017

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Initial Best Practices for Sharing Data

• When citing data, state whether data are available, and, if so, where to access them (*transparency*).

• Data must be posted to a trusted repository (FAIR). Exceptions must be identified at article submission.

• Data analysis also must be posted to a trusted repository, and reported analyses should be reproduced independently prior to publication.
How to Share BIG Data or Sensitive Data?

Big Data Sharing Meeting - September 19, 2017

Session 1: What is data sharing and who has done it
- Warren Kibbe (Duke University School of Medicine, formerly NCI)
- Brian Nosek (Center for Open Science)

Session 2: Data sharing from multiple perspectives
- Magali Haas (Cohen Veterans Bioscience)
- Kenna Shaw (University of Texas - MD Anderson Cancer Center, formerly Director NIH’s The Cancer Genome Atlas)
Session 3: Data sharing platforms today

- Vincent Ferretti (Ontario Institute for Cancer Research - OICR)
- Michael Fitzsimons (University of Chicago, Genomic Data Commons – GDC)
- Justin Guinney (Sage Bionetworks)
- Erik Lehnert (Seven Bridges Genomics)
- Benedict Paten (University of California, Santa Cruz)
- Anthony Philippakis (Broad Institute, Google Ventures)
Challenges to Open Data Sharing

• Not free - who pays?
• What are the relevant trusted repositories?
• Burden to researchers – data needs to be “sharable”
• Researchers (and funders) afraid to share sensitive data
• Administrative burden for funder – negotiate agreements, verify compliance, etc.
• Needs to be better aligned with reward structure
• Researchers want to mine their own data first, and spin off studies should be purview of postdocs etc.
Incentivizing Data Sharing

• Require (most are not there yet)
• Publicize – sharing increases research impact
• Give meaningful credit for sharing data
• Require DMP in proposal *(or data steward signoff?)*
• Evaluate extent of data sharing in renewals, applications, etc *(open data metric?)*
• Help cover costs – supplement grants, build infrastructure, ?
Thank you

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www.healthra.org