



HEALTH AND MEDICINE DIVISION

BOARD ON HEALTH SCIENCES POLICY

BOARD ON HEALTH CARE SERVICES

Changing the Culture of Data Management and Sharing — A Workshop

April 28-29, 2021



#DataSharing

NIH Data Management and Sharing Policy

- Final policy released in October 2020
- A data management and sharing plan will be required starting **January 25, 2023** for all NIH-funded research
- Policy goals:
 - Increase scientific transparency and public trust
 - Improve reliability/reproducibility
 - Enable reuse of valuable data
 - Accelerate discoveries



Workshop Sponsor - NIH Office of Science Policy

Workshop goals:

- Consider how to prepare for implementation of the policy
- Explore what is needed to foster a culture shift toward broader sharing of scientific data

2023



Workshop Planning Committee

- **Maryann Martone, Ph.D. (*co-chair*)**, University of California, San Diego
- **Richard Nakamura, Ph.D. (*co-chair*)**, Retired, NIH Center for Scientific Review
- **Christine Borgman, Ph.D.**, University of California, Los Angeles
- **Wouter Haak**, Elsevier
- **Mark Hahnel, Ph.D.**, Figshare
- **Nick Lindsay**, MIT Press
- **Elaine Mardis, Ph.D.**, Nationwide Children's Hospital/Ohio State University
- **Kristen Rosati, J.D.**, Coppersmith Brockelman PLC
- **Neil Thakur, Ph.D.**, ALS Association
- **Daniela Witten, Ph.D.**, University of Washington



Benefits of Data Sharing and FAIR Data

- Meta-analyses and expansion of data sets
- Expansion of data sets: genomics, imaging, clinical outcomes, behavior change
- Increase diversity and utility study populations
- New conclusions from old data sets, esp. medical records, population data, random sampling, exhaustive mapping, moments of time
- Efficiency (speed and cost) and exploration
- Open up science, allow citizen science
- Analyze statistics, data replicability and variability, detection of errors and dishonesty
- Increases trust in science
- Reduces temptation to cheat/trim/select



Changing Scientific Culture

- Achieving universal availability of scientific data beyond certain fields such as genomics, requires culture change.
- Changing human behavior is difficult, so what must be done to achieve this change?



Changing Scientific Culture

Infrastructure:

- Researchers need the necessary tools and access to expertise to manage the data from inception of study to end
- Tools have to well engineered and support FAIR data practices
- Focus here is on data, but data without code is not nearly as useful

Culture Shift:

Requires cooperation among:

- PI/Scientists
- Department/Institutions
- University libraries
- Influential university consortia
- Training programs
- Scientific societies and scientific leaders
- Funding organizations
- Program staff
- Scientific reviewers
- Data managers
- Publishers



Topics and Questions to Address at the Workshop

- How can sharing be made easier and more beneficial to data generators?
- What tools/resources are needed?
- What funding needs exist?
- Other challenges to discuss:
 - Incentives - social, financial, professional
 - Privacy/IP restrictions
 - Resistance to culture change



Reminders

- Workshop will be recorded and materials/videos will be uploaded to the website within a couple of weeks after the event.
- Slido platform beneath the webcast video can be used for entering comments and questions. Please include your name and affiliation.
- Full agenda over two days - reminder to speakers and moderators to please stay on time.
- Post-workshop survey will be distributed on Day 2. Please take a few minutes to share your thoughts with us!



Next: Goals for the NIH Data Management and Sharing Policy

Lyric Jorgenson, Ph.D.

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