

# NIH Data Management & Sharing Final Policy

## **Moderator:**

**Jim Luther**, Associate Vice President of Finance and Compliance Officer, Duke University

## **Panelists:**

**Dr. Carrie Wolinetz**, Associate Director of Science Policy, NIH

**Jerry Sheehan**, Deputy Director, National Library of Medicine

**Dr. Suzanne Allard**, Professor of Information Sciences, Assoc. Dean for Research, College of Communication and Information, University of Tennessee Knoxville

**Dr. Shawn Murphy**, Professor of Neurology, Mass General Brigham, Professor of Biomedical Informatics, Harvard Medical School

# COGR Data Management & Sharing Work Group

- **Suzanne Allard**, Prof., School of Information Sciences, *University of Tennessee, Knoxville*
- **Theresa Colecchia**, *Johns Hopkins University*
- **Stephanie Endy**, *Brown University*
- **Joseph Gindhart**, *Wash. University, St. Louis*
- **Keri Godin**, *Brown University*
- **Walter Goldschmidts**, *Cold Spring Harbor Laboratory*
- **JR Haywood**, *Michigan State University*
- **Melissa Korf**, *Harvard University*
- **Jennifer Lassner**, *University of Iowa*
- **Margaret Levenstein**, *University of Michigan*
- **Michael Legrand**, *University of California-Davis*
- **Jim Luther**, *Duke University*
- **Shawn Murphy**, Prof. of Neurology/Biomedical Informatics, *Mass. General Hospital & Harvard Medical School*
- **Craig Reynolds**, *University of Michigan*
- **Jackie Bendall**, Director of Contracts & Grants Administration, *COGR*
- **Toni Russo**, Administrative Officer and Policy Analyst, *COGR*

# Agenda

- Session Overview and Context
- Assumptions
  - You have read the guidance!!!
  - This is the start of a “marathon” (not a sprint)
  - COGR Workgroup will be an ongoing resource

- Today’s Objective
  - NIH Insights
  - Faculty Focus
  - Q&A and Interactive
  - Strategic and Tactical

- Next Steps



# NIH Policy Notices & Supplemental Information

- *Released October 29, 2020, **Effective January 25, 2023***
  - [NOT-OD-21-013](#) - Final NIH Policy for Data Management and Sharing
    - **Two main requirements (1) the submission of a Data Management and Sharing Plan (Plan); and (2) Compliance with the approved Plan.**
  - [NOT-OD-21-014](#) – Supplemental Information to the NIH Policy for Data Management and Sharing: **Elements of an NIH Data Management and Sharing Plan**
  - [NOT-OD-21-015](#) – Supplemental Information to the NIH Policy for Data Management and Sharing: **Allowable Costs** for Data Management and Sharing
  - [NOT-OD-21-016](#) – Supplemental Information to the NIH Policy for Data Management and Sharing: **Selecting a Repository** for Data Resulting from NIH-Supported Research



- Today, nearly twenty years after the publication of the Final NIH Statement on Sharing Research Data in 2003, we have released a *Final NIH Policy for Data Management and Sharing*.
- We hope it will be a **critical step in moving towards a culture change, in which data management and sharing is seen as integral to the conduct of research.**
- Responsible data management and sharing is good for science; it maximizes availability of data to the best and brightest minds, underlies reproducibility, honors the participation of human participants by ensuring their data is both protected and fully utilized, and provides an element of transparency to ensure public trust and accountability.



# Fostering a Culture of Scientific Data Stewardship



Guest post by Jerry Sheehan, Deputy Director, National Library of Medicine.

Guest Author

November 4, 2020

Data Sharing, Library (NLM)  
Policy, NLM Technology

Making research data broadly findable, accessible, interoperable, and reusable is essential to advancing science and accelerating its translation into knowledge and innovation. The global response to COVID-19 highlights the importance and benefits of sharing research data more openly.



*As NLM Deputy Director, Jerry Sheehan shares responsibility with the Director for overall program development, program evaluation, policy formulation, direction and coordination of all Library activities. He has made major contributions to the development and implementation of NIH, HHS, and U.S. government-wide policy related to open science, public access to government-funded information, clinical trials registration, and electronic health records.*

- As an organization **dedicated to improving access to data and information** to advance biomedical sciences and public health, NLM plays a key role in implementing the new policy and supporting researchers in meeting its requirements. **NLM maintains a number of data repositories**...that curate, preserve, and provide access to research data. NLM also maintains a longer list of **NIH-supported data repositories** that accept different types of data (e.g., genomic, imaging) from different research domains (e.g., cancer, neuroscience, behavioral sciences)....

**Dr. Carrie Wolinetz**  
**Associate Director of**  
**Science Policy, NIH**



**Jerry Sheehan,  
Deputy Director for the  
National Library of  
Medicine**





# Dr. Shawn Murphy

Professor of Neurology, Mass General  
Brigham, Professor of Biomedical Informatics,  
Harvard Medical School



# **Dr. Suzie Allard**

**Professor of Information Sciences, Associate  
Dean for Research in the College of  
Communication and Information, University  
of Tennessee - Knoxville**



# About what I'm sharing...

Study knowledge creation, specifically the role of data

→ The data lifecycle from the perspective of:

- Researchers
- Institutions

in academe, industry, government

→ Scientific cyberinfrastructure sustainability

Suzie Allard, Ph.D.

Chancellor's Professor; Associate Dean for Research, College of Communication & Information

Co-PI on NSF funded DataONE (went self-sustainable 1/2020)

PI on several funded projects for data librarian/manager masters education

Lead on efforts to bring World Data System Program Office to the U.S.

# Researcher Perspective

- Most researchers are positive towards data sharing/data reuse.
- Most important for their reusing others' data are details of collection/quality assurance, metadata standards and provenance. (even if they don't have good practices themselves)
- There is uneven familiarity with the concept of a trusted repository.

Questions researchers have:

- Who is the authoritative source I should consult about these requirements? My institution? NIH?
- When doing the work to meet these requirements how do I overcome these concerns?
  - Publication first
  - Not enough time
  - Data rights
  - Not enough funding
- What financial and data management support for meeting these requirements is provided so I can concentrate on research?

# Institutional Perspective

- RDS at institutions varies widely.
- Work detailing collection/quality assurance, metadata standards and detailed provenance usually is often resident with the researcher.
- Many institutions are challenged by data repository issues.

Questions institutions need to address:

- What funding mechanism is in place for us to meet NIH requirements?
- How do we manage roles played by the researchers & the institution in accountability/compliance?
- How do we move away from individual data holdings to trusted repositories? How to support this?
- What about sustainability? How to support a repository used by multiple institutions?