

*The National Academies of*  
SCIENCES • ENGINEERING • MEDICINE

*Board on Health Sciences Policy  
Board on Health Care Services*

## Changing the Culture of Data Management and Sharing A Workshop

**April 28-29, 2021**  
Virtual Workshop

### **TIMELINE:**

April 28, 2021: 11:00 AM – 4:10 PM ET

April 29, 2021: 11:00 AM – 4:00 PM ET

**STATEMENT OF TASK:** In response to a request from the NIH Office of Science Policy, a planning committee of the National Academies of Sciences, Engineering, and Medicine will convene a two-day virtual public workshop to discuss the challenges and opportunities for researchers, institutions, and funders to establish effective data management and sharing practices. The objective of the workshop is to examine strategies, resources, and promising practices for developing and evaluating data management and sharing plans, as well as to discuss how researchers can effectively share scientific data over the course of the data life cycle.

Input will be sought from a variety of perspectives, including researchers, data repository managers, funding institutions, publishers, research participants, and other stakeholders to include a diversity of biomedical research fields and disciplines. With an emphasis on illustrative case studies, real world examples, and promising practices, potential topics may include:

- Addressing overarching strategies for managing and sharing data, taking into consideration diverse needs (e.g., human vs non-human data, type and size, data generators vs data users);
- Assessing value of shared data and the development and evaluation of data management and sharing plans, which may include discussions of:
  - best practices for repositories to collect the metrics needed to make such assessments,
  - the extent to which data value was anticipated and planned for prior to generating or sharing data, and
  - how this might inform prospective planning for sharing;
- Monitoring and evaluating data management and sharing practices, including discussion of appropriate metrics for timelines of data availability and life cycles of different types of scientific data; and
- Considering educational and other resource needs for responsible data sharing practices.

The workshop planning committee will develop the agenda for the workshop, select and invite speakers and discussants, and moderate or select moderators for the discussions. At the end of each workshop day, key points from individual speakers will be summarized and shared with the audience by a moderator. The workshop website will contain presentations from the speakers who provide the National Academies with permission to share their slides and the video of the webcast from the workshop.

# DAY 1: Wednesday, April 28, 2021

11:00 a.m.     **Introduction and Charge to the Workshop Speakers and Participants**

MARYANN MARTONE, *Workshop Planning Committee Co-Chair*  
Professor, Neurosciences  
UCSD

RICHARD NAKAMURA, *Workshop Planning Committee Co-Chair*  
(Retired) Former Director, Center for Scientific Review  
National Institutes of Health (NIH)

*Moderator: Richard Nakamura*

11:10 a.m.     **Goals for the NIH Data Management and Sharing Policy**

LYRIC JORGENSON  
Deputy Director for the Office of Science Policy  
National Institutes of Health (NIH)

11:20 a.m.     **Keynote Presentation – What Has the COVID-19 Pandemic Taught Us About Data Sharing and Open Science?**

PATRICIA BRENNAN  
Director  
National Library of Medicine

11:35 a.m.     **Clarifying Questions from the Audience**

11:40 a.m.     **Panel Discussion: Perspectives on Data Management and Sharing Across Different Types of Data**

*Moderator: Maryann Martone, UCSD*

ATUL BUTTE  
Priscilla Chan and Mark Zuckerberg Distinguished Professor  
UCSF

LARA MANGRAVITE  
President  
Sage Bionetworks

ALEXANDER ROPELEWSKI  
Operations Director  
Brain Image Library

JOSHUA WALLACH  
Assistant Professor of Epidemiology  
Yale School of Public Health

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## SESSION I. STRATEGIES FOR MANAGING AND SHARING DATA: DIVERSE NEEDS AND CHALLENGES

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*Moderator: Elaine Mardis, Nationwide Children's Hospital*

Session Objectives:

- Explore challenges and potential solutions to effective data management and sharing across a range of scientific disciplines.
- Discuss how data can be effectively shared over the course of the data life cycle.

12:10 p.m.     **Data Formatting: Exploring Challenges and Potential Solutions**

DAVID HAUSSLER  
Investigator, Howard Hughes Medical Institute  
Distinguished Professor, Biomolecular Engineering  
UC Santa Cruz

ADAM FERGUSON  
Associate Professor  
Department of Neurological Surgery, Brain and Spinal Injury Center  
UCSF

12:30 p.m.     **General Challenges with Data Sharing: Investigator and Repository Perspectives**

REBECCA KOSKELA  
Executive Director  
Research Data Alliance

RUSSELL POLDRACK  
Albert Ray Lang Professor of Psychology  
Stanford University

JEREMY WOLFE  
Director, Visual Attention Lab  
Brigham & Women's Hospital  
Professor of Ophthalmology & Radiology  
Harvard Medical School

12:55 p.m.     **Break**

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## SESSION II. MONITORING AND EVALUATING DATA MANAGEMENT AND SHARING PRACTICES

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*Moderator: Wouter Haak, Elsevier*

Session Objectives:

- To examine possible approaches for monitoring and measuring the success of data sharing and management across different types of scientific data.

1:20 p.m.      **Exploring the Current State of Data Citation Methods and Tools**

DANIELLA LOWENBERG  
Director, Make Data Count  
California Digital Library

ALBERTO ZIGONI  
Market Development Director  
Research Data Management Solutions  
Elsevier

1:40 p.m.      **Brief Discussion with Speakers**

1:45 p.m.      **What are the Critical Elements of a Successful Data Sharing Plan?**

ROBERT HANISCH  
Director, Office of Data and Informatics  
NIST

2:00 p.m.      **Brief Discussion with Speakers**

2:05 p.m.      **Working to Establish Best Practices for Data Sharing**

ELAINE MARTIN  
Director and Chief Administrative Officer, Countway Library  
Harvard University; RDMLA

2:20 p.m.      **Panel Discussion with the Speakers**

2:35 p.m.      **Break**

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### **SESSION III. ENCOURAGING UPTAKE OF DATA SHARING IN THE SCIENTIFIC COMMUNITY**

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*Moderator: Mark Hahnel, Figshare and Daniela Witten, University of Washington*

Session Objective: Explore the needs of researchers with respect to implementing the new NIH data sharing policy, and understand what would encourage and promote policy adherence.

2:55 p.m.      ***Moderated Panel Discussion***

*Questions for the Panelists:*

- What does a modern laboratory need (e.g., tools/infrastructure) in order to be prepared to implement the policy?
- What are the needs around training and education for laboratories to successfully implement the new data sharing policy?
- How can we ensure that there will be uptake of the new NIH policy in the scientific community?

*Panelists:*

TIMOTHY COETZEE  
Chief Advocacy, Services, & Science Officer  
National Multiple Sclerosis Society

SCOTT FRASER  
Provost Professor and Director of Scientific Initiatives  
University of Southern California

RICK GILMORE  
Professor of Psychology  
Penn State University

CAROLE GOBLE  
Professor of Computer Science  
University of Manchester

SARAH NUSSE  
Professor of Statistics  
Iowa State University

LETISHA WYATT  
Assistant Professor of Neurology, School of Medicine  
Director of Diversity in Research, OHSU Research & Innovation  
Oregon Health Science University (OHSU)

3:35 p.m.     **Q&A with the Speakers and Participants**

3:55 p.m.     **Reflections on Day 1 and Preview of Day 2**

MARYANN MARTONE, *Workshop Planning Committee Co-Chair*  
Professor, Neurosciences  
UCSD

RICHARD NAKAMURA, *Workshop Planning Committee Co-Chair*  
(*Retired*) Former Director, Center for Scientific Review  
National Institutes of Health (NIH)

4:10 p.m.     **Adjourn Workshop Day 1**

## DAY 2: Thursday, April 29, 2021

11:00 a.m. ET **Welcome and Overview of Day 2**

MARYANN MARTONE, *Workshop Planning Committee Co-Chair*  
Professor, Neurosciences  
UCSD

RICHARD NAKAMURA, *Workshop Planning Committee Co-Chair*  
(Retired) Former Director, Center for Scientific Review  
National Institutes of Health (NIH)

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### SESSION IV. VALUE AND COSTS OF MANAGING AND SHARING DATA

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*Moderator: Christine Borgman, UCLA*

Session Objective: To understand from a variety of perspectives what constitutes good practices to ensure that data is reproducible.

11:10 a.m. **Realizing the Value of Data Management from the Laboratory Side**

JOHN BORGI  
Manager of Research and Instruction  
Lane Medical Library  
Stanford University

ANA VAN GULICK  
Government and Funder Lead  
Figshare

11:25 a.m. **Data Quality and Other Factors that Make Data More Likely to be Reused**

RAFAEL IRIZARRY  
Professor of Applied Statistics  
Harvard University

DANIEL GOROFF  
Vice President and Program Director  
Alfred P. Sloan Foundation

IRENE PASQUETTO  
Assistant Professor of Information  
University of Michigan

11:55 a.m. **Questions for the Speakers**

12:05 p.m. **Reflections from the Field and Panel Discussion**

JAN BJAALIE  
Professor, Infrastructure Development Director  
University of Oslo and EU Human Brain Project

12:25 p.m. **Break**

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## **SESSION V. SHAPING A CULTURE OF DATA SHARING – REDUCING BARRIERS AND INCREASING INCENTIVES**

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### Session Objectives:

- Examine legal and ethical issues that can potentially create barriers to large-scale data sharing, including evolving privacy laws, informed consent, and ethical concerns.
- Understand opportunities and barriers to encouraging a culture of data sharing.
- Explore the impact of funder policies (other than sharing mandates) on widespread data sharing.

12:45 p.m. **Overview of Legal Issues around Data Sharing**

KRISTEN ROSATI  
Attorney  
Coppersmith Brockelman PLC  
Past President, American Health Law Association

12:55 p.m. **Seeking “Informed” Consent for Large-Scale Data Sharing**

MARK ROTHSTEIN  
Herbert F. Boehl Chair of Law and Medicine  
Founding Director of the Institute for Bioethics, Health Policy and Law at the  
University of Louisville School of Medicine

1:05 p.m. **Creating Good Data Governance: The Evolving Role of the University as Gate Keeper and Cheerleader for Data Sharing**

CORA HAN  
Chief Health Data Officer  
UC Health, University of California

1:15 p.m. **Implementing the NIH Data Management and Sharing Policy: The Evolving Ethics of Data Sharing**

ANITA ALLEN  
Henry R. Silverman Professor  
University of Pennsylvania Law School

1:25 p.m. **Discussion/Q&A with the Speakers and Participants** (*Moderator: Kristen Rosati, Attorney, Coppersmith Brockelman PLC*)

1:45 p.m.      **Encouraging Data Sharing Outside of Mandates**

NEIL THAKUR  
Chief Mission Officer  
ALS Association

ASHLEY FARLEY  
Associated Officer, Knowledge & Research Services  
Bill & Melinda Gates Foundation

MARYROSE FRANKO  
Executive Director  
Health Research Alliance (HRA)

2:15 p.m.      **Discussion/Q&A with the Speakers and Participants** (*Moderator: Neil Thakur, ALS Association*)

2:35 p.m.      **Break**

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## **SESSION VI. IMPLEMENTING THE NIH DATA MANAGEMENT AND SHARING POLICY: ARE WE READY FOR 2023?**

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Session Objectives:

- Examine common themes and takeaways from the earlier workshop sessions.
- Explore possible challenges to the implementation of the NIH data management and sharing policy from a variety of stakeholder perspectives.
- Consider possible actions that can be taken to help different stakeholder groups prepare for and be successful with complying with the NIH data management and sharing policy.

2:55 p.m.      **Multi-Stakeholder Panel with Select Speakers**

***Moderator:***

RICHARD NAKAMURA, *Workshop Planning Committee Co-Chair*  
(*Retired*) Former Director, Center for Scientific Review  
National Institutes of Health (NIH)

***Panelists:***

CHRISTINE BORGMAN  
Distinguished Research Professor, Information Studies  
UCLA

PHILIP BOURNE  
Founding Dean, School of Data Science  
Professor of Biomedical Engineering  
University of Virginia

SUSANNA-ASSUNTA SANSONE  
Associate Professor, Data Readiness  
Associate Director, Oxford e-Research Centre

University of Oxford

MARGARET SUTHERLAND  
Program Manager  
Chan Zuckerberg Initiative

NEIL THAKUR  
Chief Mission Officer  
ALS Association

LETISHA WYATT  
Assistant Professor of Neurology, School of Medicine  
Director of Diversity in Research, OHSU Research & Innovation  
Oregon Health Science University (OHSU)

3:45 p.m.     **Reflections from the Workshop and Final Comments**

MARYANN MARTONE, *Workshop Planning Committee Co-Chair*  
Professor, Neurosciences  
UCSD

4:00 p.m.     **Adjourn Workshop Day 2**