


# Shaping the next 10 years in Data Sharing: Building on the gains made and looking ahead to the next 10 years in advancing human health

**November 16<sup>th</sup>, 2023, 8:30am-4:00pm EST**  
**Room 120, National Academy of Medicine,**  
**2101 Constitution Ave. NW, Washington, DC 20418**

<b>8:30am</b> - Registration and coffee
<b>9:00am</b> - <b>Victor J Dzau, M.D.</b> , President, National Academy of Medicine— <b>Welcome</b>
<p><b>The 2015 IOM <a href="#">Sharing Clinical Trial Data: Maximizing Benefits, Minimizing Risk</a> Recommendations and Challenges ahead</b> Should we collectively set a new “north star” for the next 10 years?</p> <p>Moderator: <b>Bernard Lo, M.D.</b>, Professor of Medicine Emeritus, University of California San Francisco</p> <p><b>Jeffrey M. Drazen, M.D.</b> NEJM Group Editor, <i>The New England Journal of Medicine</i>  <b>Professor Arti K. Rai</b>, Elvin R. Latty Professor of Law, Duke Law  <b>Ida Sim M.D., Ph.D.</b>, Professor of Medicine, University of California San Francisco; Vivli co-founder  <b>Joanne Waldstreicher, M.D.</b>, Independent Director, Becton Dickinson and Structure Therapeutics;  Former Chief Medical Officer, Johnson &amp; Johnson (retired); Faculty Affiliate, Division of Medical Ethics,  New York University School of Medicine</p>
<p><b>The Value of Data Sharing Realized</b> This session will focus on real-life case studies that show the fruition of efforts to share data and its impact on science.</p> <p>Moderator: <b>Murray Stewart, M.D.</b>, Chief Medical Officer, Rhythm Pharmaceuticals, Inc., Vivli Board member</p> <p><b>Ricardo Jorge de Oliveira Ferreira, Ph.D.</b>, Auxiliary Researcher at the Nursing Research, Innovation and Development Centre of Lisbon (CIDNUR), Nursing School of Lisbon (ESEL)  <b>Richard Liwski</b>, Chief Technology Officer and Director, Critical Path Institute’s Data Collaboration Center  <b>Rebecca Li, Ph.D.</b>, CEO and co-founder, Vivli  <b>Sarah Nevitt, Ph.D.</b>, Senior Research Fellow, Centre for Reviews and Dissemination, University of York  <b>Ronald Summers, M.D., Ph.D.</b>, Senior Investigator, Imaging Biomarkers and Computer-Aided Diagnosis Laboratory, NIH Clinical Center</p>
Coffee break
<p><b>Credit and incentivizing the academic culture</b> With the recent policy announcements by the White House and the newly updated NIH Data Management and Sharing Policy, movements are afoot to prompt academic researchers to share. What more can be done to encourage academic researchers to share their data by leveraging incentives?</p>



Moderator: **Barbara Bierer, M.D.**, Faculty Director, MRCT Center, Brigham and Women's Hospital; Professor of Medicine, Harvard Medical School; Director Regulatory Foundations, Ethics and Law, Harvard CTSA; Vivli co-founder

**Elliott Antman, M.D.**, Director, Harvard Postgraduate Program in Clinical/Translational Science, Professor of Medicine, Harvard Medical School

**Daniel Ernest Ford, M.D., M.P.H.**, Director & Professor of Medicine, Senior Associate Dean for Clinical and Translational Research, Johns Hopkins Institute for Clinical and Translational Research

**Steven Goodman, M.D., M.H.S., Ph.D.**, Professor of Epidemiology and Population Health and of Medicine, Stanford University

**Benjamin Pierson**, Deputy Director, Enterprise Data, Bill & Melinda Gates Foundation

Lunch

**Key technologies that will influence data sharing (Machine learning, AI)**

What role with key technologies such as Large Language Models and other key technological advances play in data sharing? What are the key motivating factors and obstacles that will need to be addressed?

Moderator: **Ida Sim M.D., Ph.D.**, Professor of Medicine, University of California San Francisco; Vivli co-founder

**Jonathan Carlson, Ph.D.**, General Manager, Life Sciences Research and Incubations, Microsoft

**Subha Madhavan, Ph.D.**, Vice President & Head of AI/ML, Quantitative & Digital Sciences, Global Biometrics & Data Management, Pfizer Inc.

**Philip Payne, Ph.D., FACMI, FAMIA, FAIMBE, FIAHSI**, Director, Institute for Informatics, Data Science and Biostatistics (I2DB); Chief Data Scientist and Associate Dean of Health Information & Data Science; Washington University School of Medicine in St. Louis

**Jane Perlmutter, M.B.A., Ph.D.**, President and Founder, Gemini Group Consultancy

**Regulations and policies to promote data sharing and re-use**

Given recent shifts in national policies to promote data re-use as well as efforts by publishers to promote data reuse, what more can be done by regulators, national governments, publishers and other key actors to advance data sharing and subsequent re-use?

Moderator: **Michael Stebbins, Ph.D.**, President Science Advisors. Vivli Board Chair

**Steven Kern, Ph.D.**, Executive Director, Global Health Labs

**Michael Lauer, M.D.**, Deputy Director for Extramural Research, NIH Office of the Director

**Deven McGraw, J.D., M.P.H, LL.M.**, Lead, Data Stewardship and Data Sharing, Invitae

**Sharon Terry, M.A.**, Chief Executive Officer, Genetic Alliance

**Shaping the inputs and direction for the next 10 years – All Participants**

4 breakout sessions – led by moderators:

- Academic culture change
- Key technologies/AI
- Regulations and policies to promote data re-use
- Visioncasting

**A way forward**

Actions and next steps from breakout groups