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 16th, 2023
Room 120, National Academy of Medicine,
2101 Constitution Ave. NW, Washington, DC 20418

Registration and coffee

Victor J Dzau—Welcome

The 2015 IOM Sharing Clinical Trial Data: Maximizing Benefits, Minimizing Risk Recommendations and Challenges ahead
Should we collectively set a new “north star” for the next 10 years?

Moderator: Bernard Lo, M.D., Professor of Medicine Emeritus, University of California San Francisco

Jeffrey M. Drazen, M.D. NEJM Group Editor, The New England Journal of Medicine
Professor Arti K. Rai, Elvin R. Latty Professor of Law, Duke Law
Joanne Waldstreicher, M.D., Independent Director, Becton Dickinson and Structure Therapeutics;
Former Chief Medical Officer, Johnson & Johnson (retired); Faculty Affiliate, Division of Medical Ethics, New York University School of Medicine

The Value of Data Sharing Realized
This session will focus on real-life case studies that show the fruition of efforts to share data and its impact on science.

Moderator: Murray Stewart, M.D., Chief Medical Officer, Rhythm Pharmaceuticals, Inc., Vivli Board member

Ricardo Jorge de Oliveira Ferreira, Ph.D., Auxiliary Researcher at the Nursing Research, Innovation and Development Centre of Lisbon (CIDNUR), Nursing School of Lisbon (ESEL)
Richard Liwski, Chief Technology Officer and Director, Critical Path Institute’s Data Collaboration Center
Rebecca Li, Ph.D., CEO and co-founder, Vivli
Sarah Nevitt, Ph.D., Senior Research Fellow, Centre for Reviews and Dissemination, University of York
Ronald Summers, M.D., Ph.D., Senior Investigator, Imaging Biomarkers and Computer-Aided Diagnosis Laboratory, NIH Clinical Center

Coffee break

CREDIT and incentivizing the academic culture
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?
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

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

Michael Lauer, M.D., Deputy Director for Extramural Research, NIH Office of the Director
Deven McGraw, J.D., M.P.H, LLM, 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