

The National Academies of
SCIENCES • ENGINEERING • MEDICINE

**Building Data Capacity for Patient-Centered Outcomes Research:
An Agenda for 2021 to 2030**

**Virtual Workshop 3: A Comprehensive Data Ecosystem for
Patient-Centered Outcomes Research**

JUNE 14, 2021, 11 AM – 5 PM EDT

OBJECTIVES FOR THE WORKSHOP

- Discuss how research and data collaborations can evolve to meet PCOR research and data capacity challenges, and how HHS can support effective research and data collaborations
- Identify barriers and potential solutions to the access and use of linked public data, and to the access and use of linked public and private/proprietary data
- Discuss the feasibility and utility of developing a phased-in approach to building the interoperable data capacity for patient-centered outcomes research with existing databases in HHS, other Federal Departments and the private sector

11:00-11:05 AM EDT

Goals for the Workshop

GEORGE ISHAM (Committee Chair) HealthPartners Institute

11:05 AM-12:50 PM EDT

Federal Partners for PCOR

Moderators: JULIE BYNUM, University of Michigan and
GEORGE HRIPCSAK, Columbia University

Speakers:

MICKY TRIPATHI, Office of the National Coordinator for Health
Information Technology

ALLISON OELSCHLAEGER, Office of Enterprise Data &
Analytics, Centers for Medicare and Medicaid Services

MEAGAN KHAU, Office of Minority Health, Centers for
Medicare and Medicaid Services

MITRA ROCCA, Center for Drug Evaluation and Research, Food and Drug Administration

ADI GUNDLAPALLI, Public Health Informatics Office, Centers for Disease Control and Prevention

ALISON CERNICH, Eunice Kennedy Shriver National Institute of Child Health and Human Development

JACOB KEAN, Salt Lake City VA Health Care System, Department of Veterans Affairs and University of Utah

12:50-1:00 PM EDT

Break

1:00-2:00 PM EDT

State-Level Data and Data Collaborations

Moderators: ROBERT GOERGE, University of Chicago and LISA IEZZONI, Massachusetts General Hospital

Speakers:

LYNN BLEWETT, State Health Access Data Assistance Center

MARSHA LILLIE-BLANTON, George Washington University

TODD GILMER, University of California, San Diego

CLAUDIA STEINER, Kaiser Permanente Research

2:00-2:50 PM EDT

Clinical Trial Networks and Collaborations

Moderators: DAVID MELTZER, University of Chicago and CONSTANTINE GATSONIS, Brown University

Speakers:

RUTH CARLOS, University of Michigan

LAURA ESSERMAN, University of California, San Francisco

LESLEY CURTIS, Duke University

2:50-3:05 PM EDT

Break

3:05-4:00 PM EDT

Public-Private Partnerships

Moderators: ELIZABETH MCGLYNN, Kaiser Permanente Research and MIGUEL MARINO, Oregon Health & Science University

Speakers:

ATUL BUTTE, University of California, San Francisco

VINCENT MOR, Brown University

MARC OVERHAGE, Anthem

4:00-4:50 PM EDT

Collaborations with Patient Groups

Moderators: JOHN F.P. BRIDGES, The Ohio State University and ANGELA DOBES, Crohn's & Colitis Foundation

Speakers:

PAT FURLONG, Parent Project Muscular Dystrophy

JAMES LEWIS, University of Pennsylvania

MARC NATTER, Harvard University

4:50-5:00 PM EDT

Wrap-up

GEORGE ISHAM (Committee Chair) HealthPartners Institute
