

*The National Academies of*  
SCIENCES • ENGINEERING • MEDICINE

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

**Virtual Workshop 2: Data Standards, Methods, and Policy**

MAY 24, 2021, 11 AM – 5 PM EDT

**OBJECTIVES FOR THE WORKSHOP**

- Identify data standards and methods that can make the PCOR data infrastructure more useful for research and other data needs.
- Identify data policies that are needed to facilitate the continued development and operation of the PCOR data infrastructure
- Discuss what HHS is best positioned to address and support, and how the agency could maximize resources available for the PCOR data infrastructure (representing 4% of the PCOR trust fund), in the context of the HHS public mission, authorities, programs, and data resources.

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11:00-11:05 AM EDT

**Goals for the Workshop**

GEORGE ISHAM (Committee Chair) HealthPartners Institute

11:05 AM -1:05 PM  
EDT

**PCOR Data Standards**

Discussion questions:

- What data standards could make the PCOR data infrastructure more useful for research and other data needs? What data standards are likely to become more relevant looking forward? What needs to be prioritized?
- What role can ASPE play in supporting effective standards to build data capacity that supports PCOR studies? What characteristics of HHS' public mission, programs, or authorities could be leveraged?

**Moderators:** GEORGE HRIPCSAK, Columbia University and DAVID MELTZER, University of Chicago

**Speakers:**

JOHN HALAMKA, Mayo Clinic

SHAUN GRANNIS, Regenstrief Institute

EVELYN GALLEG0, EMI Advisors

RACHEL RICHESSON, University of Michigan

PATRICK RYAN, Janssen Research and Development

VG VINOD VYDISWARAN, University of Michigan

1:05-1:20 PM EDT

**Break**

1:20-3:00 PM EDT

**PCOR Methods**

Discussion questions:

- What emerging methods are likely to be most relevant for the PCOR data infrastructure looking forward? What are the most important research and data challenges?
- What computing advances, innovative health information technologies, and methodologies might present opportunities going forward?
- What role can ASPE play in supporting effective methods for PCOR studies? What characteristics of HHS' public mission, programs, or authorities could be leveraged?

**Moderators:** MIGUEL MARINO, Oregon Health & Science University and CONSTANTINE GATSONIS, Brown University

**Speakers:**

NIGAM SHAH, Stanford University

SHARON-LISE NORMAND, Harvard University

SHERRI ROSE, Stanford University

LARA MANGRAVITE, Sage Bionetworks

NIROSHA MAHENDRARATNAM LEDERER, Aetion

3:00-3:15 PM EDT

**Break**

3:15-4:55 PM EDT

**Data Policies and Other Data Infrastructure Considerations**

Discussion questions:

- What data policies are likely to be most relevant for the PCOR data infrastructure looking forward?
- What role can ASPE play in supporting these policies for PCOR studies? What characteristics of HHS' public mission, programs, or authorities could be leveraged?

**Moderators:** DEBORAH ESTRIN, Cornell Tech and  
PAUL TANG, Palo Alto Medical Foundation and Stanford Clinical  
Excellence Research Center

**Speakers:**

PAMELA RILEY, Government of the District of Columbia

ABEL KHO, Northwestern University

JULIA ADLER-MILSTEIN, University of California, San Francisco

DEVEN MCGRAW, Ciitizen

DON DETMER, University of Virginia

4:55-5:00 PM EDT

**Wrap-up**

GEORGE ISHAM (Committee Chair) HealthPartners Institute

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