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

Virtual Workshop 1: Looking Ahead at Data Needs

MAY 3, 2021, 11 AM – 5 PM EDT

OBJECTIVES FOR THE WORKSHOP

- Provide a high-level overview of what kind of data are included in the patient-centered outcomes research data infrastructure.
- Identify key questions that stakeholders are most likely to want answered going forward, including general themes that cut across health conditions and circumstances.
- Discuss implications of the broadened statutory scope for PCOR.
- Identify gaps in what stakeholders need and what the infrastructure allows. Consider both limitations in the existing data and improvements that could be made to new data collections (e.g., at point of care or in prospective studies).
- Discuss what questions cannot be answered and who is not served by the current PCOR data infrastructure.
- Discuss what HHS is best positioned to address 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.

11 AM-11:05 AM EDT	**Goals for the Workshop** GEORGE ISHAM (Committee Chair) HealthPartners Institute
11:05-11:30 AM EDT	**Overview of the Data Infrastructure for Patient-Centered Outcomes Research** **Moderator:** GEORGE ISHAM BENJAMIN SOMMERS, Deputy Assistant Secretary for Health Policy, ASPE NANCY DE LEW, Associate Deputy Assistant Secretary for Health Policy, ASPE SCOTT R. SMITH, Director, Division of Healthcare Quality and Outcomes, ASPE

11:30 AM-1:00 PM EDT	**PCOR Data Infrastructure Limitations and Opportunities: Disparities and Health Equity Research**

Discussion questions:
- What are the limitations of the PCOR data infrastructure in terms of:
    - disparities in the data, including knowledge about patient outcomes, taking into consideration differences in patient preferences and values
    - challenges associated with using the data to understand disparities and health equity
    - lack of data on some populations
- What are opportunities and priorities for enhancing data capacity in this area?
- What data capacity challenges is HHS best positioned to address in the context of their public mission, authorities, programs, and data resources?

Moderator: OLUWADAMILOLA (LOLA) FAYANJU, Duke University

Speakers:

KAREN JOYNT MADDOX, Washington University in St. Louis

MEGAN MORRIS, University of Colorado

MITCHELL LUNN, Stanford University

KALEAB ABEBE, University of Pittsburgh

THOMAS SEQUIST, Harvard University and Brigham & Women's Hospital

1:00-1:10 PM EDT	**Break**

1:10-1:30 PM EDT	**PCOR Data Infrastructure Limitations and Opportunities: COVID-19 as Use Case**

Moderator: PAUL TANG**,** Palo Alto Medical Foundation and Stanford Clinical Excellence Research Center

Speaker: DAVID MELTZER, University of Chicago

1:30-2:45 PM EDT	**Patient Perspectives on Data Needs**

Discussion questions:
- Looking ahead, what are the main data needs?
- What are the implications of the (recently broadened) statutory scope for PCOR?
- What questions cannot be answered and who is not served by the current PCOR data infrastructure?
- What new data sources could be incorporated into the PCOR data infrastructure?
- What data capacity challenges is HHS best positioned to address in the context of their public mission, authorities, programs, and data resources?

Moderator: ANGELA DOBES, Crohn's & Colitis Foundation

Speakers:

REBEKAH ANGOVE, Patient Advocate Foundation

GARY EPSTEIN-LUBOW, Brown University

ELISABETH OEHRLEIN, National Health Council

BRAY PATRICK-LAKE, Evidation Health

2:45-3:05 PM EDT	**Break**

3:05-4:55 PM EDT	**Researcher Perspectives on Data Needs**

Discussion questions:
- Looking ahead, what are the main data needs?
- What are the implications of the (recently broadened) statutory scope for PCOR?
- What questions cannot be answered and who is not served by the current PCOR data infrastructure?
- What new data sources could be incorporated into the PCOR data infrastructure?
- What data capacity challenges is HHS best positioned to address in the context of their public mission, authorities, programs, and data resources?

Moderator: ELIZABETH MCGLYNN, Kaiser Permanente Research

Speakers:

ANDREW BAZEMORE, American Board of Family Medicine

ROBERT CALIFF, Verily

DAVID CELLA, Northwestern University

GISELLE CORBIE-SMITH, University of North Carolina

SCOTT RAMSEY, Fred Hutch

KURT STANGE, Case Western Reserve University

4:55-5:00 PM EDT	**Wrap-up** GEORGE ISHAM (Committee Chair) HealthPartners Institute