

### **EVIDENCE MOBILIZATION ACTION COLLABORATIVE**

Winter 2020 Update

**Colleagues**: Thank you for your engagement with the <u>Evidence Mobilization Action Collaborative (EMAC)</u>, an activity of the National Academy of Medicine (NAM) <u>Leadership Consortium</u>: <u>Collaboration for a Value & Science-Driven Learning Health System</u>. Below are highlights from EMAC's work.

Please be in touch for additional information or to indicate an interest in participating in any activity noted. **Mahnoor Ahmed,** Associate Program Officer, <u>mahmed@nas.edu</u>

#### **FOCUS OF RECENT MEETINGS**

- **February 20, 2020**: Convening of the <u>Digital Health Action Collaborative (DHAC</u>) on individual access and control of health data. (<u>event page</u>)
- **February 13, 2020**: Strategy discussion with the steering committee members and working group co-chairs of the Generating Stakeholder Demand for Data Sharing, Linkage, and Use initiative.
- **January 23, 2020**: A meeting of the EMAC on the evolving trends in data privacy and implications for secondary use of health data. (event page)
- **August 23, 2019**: Building partnerships and implementing principles for a health system that shares data for continuous improvement (event page)

### **COLLABORATIVE ONGOING NAM PROJECTS: EMAC AND EMAC-RELATED**

Collaborative projects are intended to: 1) identify issues of common interest and marshal needed leadership; 2) develop tools and networks needed for progress; and 3) explore joint leadership possibilities through Collaborative-authored Perspective papers and publications. Ongoing activities include:

- Generating stakeholder support and demand for leveraging and sharing data for continuous learning focus: organization of key stakeholder groups health care executives, patient and family engagement leaders, and research oversight thought leaders identify approaches for building support for data sharing, linkage, and use as well as principles for a continuous learning. Outcomes: NAM Special Publication.
- Improving understanding of heterogeneous treatment effects (HTE) for patient-centered care. Summary of a meeting that occurred on May 31, 2018 which explored the inherent limitations of using group data to guide treatment decisions for individuals. <a href="NAM Special Publication">NAM Special Publication</a> published in 2019.
- Individual Participant Data Sharing for Continuous Learning. An NAM Perspective paper that reviews examples of successful individual participant data (IPD) sharing initiatives and repositories, presents action items for accelerating progress around IPD sharing, and outlines areas that could benefit from additional research and pilot testing to promote cultural change needed to support ongoing IPD sharing.
- Institutional oversight practices for health system evaluations. An expert discussion paper that will present a range of different review approaches that institutions may employ to oversee evaluations of health systems interventions that are not subject to the Common Rule.

# **EMAC-RELATED COLLABORATIVE PROJECTS UNDER CONSIDERATION**

• Potential projects in health data privacy: 1.) Formation of a sub working group to identify and refine the dashboard measures. 2.) Collation of case studies and best practices for data sharing and obtaining consent. 3.) Development of an approachable summary of challenges in data privacy.

#### **EVIDENCE MOBILIZATION ACTION COLLABORATIVE**

Participating Organizations

AcademyHealth

Aetna

AHIP AHA

Anthem, Inc. Apple Inc.

**AAMC** 

AstraZeneca

AthenaHealth

**Baylor Scott & White** 

Beth Israel Deaconess Medical

Center

Blue Cross and Blue Shield Boston Children's Hospital Brigham and Womn's

California Precision Medicine

Consortium **CMTP** 

Children's Hospital of Philadelphia

Children's Mercy Hospital,

Kansas City Christiana Care

AARP American Medical Association

(AMA)

Geisinger

Georgetown University Harvard University

Friends of Cancer Research

Health Care Systems Research

Cincinnati Children's Hospital

Council of Medical Specialty

Network Health Hats

Ciana

Cleveland Clinic

Cornell University

Crowell & Moring

**Duke University** 

**Emory University** 

**ECRI Institute** 

**Epic Systems** 

Societies (CMSS)

Henry Ford Health System Hospital Corporation of America (HCA) Institute for Healthcare Improvement

Intermountain Healthcare

Janssen

Johns Hopkin University

Johnson & Johnson Kaiser Permanente Mayo Clinic Medtronic Mighty Casey Media

Milken Institute

National Alliance on Mental

Illness (NAMI) National Partnership for Women & Families National Pediatric Cardiology **Quality Improvement** 

Collaborative

**OCHIN** 

Parkinson's Foundation

Partners HealthCare

**PCORI** PatientsLikeMe **Purdue University** Quintiles, Inc.

Sanofi Society for Participatory

Medicine **Temple University Tufts University** University of Alabama UC, San Francisco UnitedHealth Group University of Maryland University of Michigan University of Pennsylvania Vanderbilt University Washington University in St.

Louis Yale University X4 Health

Federal agencies:

NSF

U.S. DHHS

- Office of the Secretary

AHRQ - CDC - CMS - FDA - NIH U.S. DOD U.S. DVA

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Josephine Briggs, PCORI Susan DeVore, Premier, Inc.

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