



## National Academy of Medicine Leadership Consortium Clinical Effectiveness Research Innovation Collaborative



January 23, 2020

Keck Center

Room 100

500 Fifth Street, NW | Washington, DC

**Meeting Focus:** An exploration of the evolution of data privacy and the implications for secondary use of health data in support of a learning health system.

**Motivating questions:**

1. **Vision:** What would create the ideal conditions for health data access that benefits and protects individuals while also advancing the public good?
2. **Barriers:** What are the current sociocultural, regulatory, organizational, and technical challenges to ensuring availability of health data to advance the public good while also guaranteeing transparency and individual control over personal health data use?
3. **Use Cases:** Can approaches to data use and access from other sectors be applied to health data?
4. **Indicators of Progress:** How do we evaluate applications of health data to ensure that it is being used effectively to improve population health without sacrificing transparency and individual privacy?

**Outcomes Anticipated:** Identify actions NAM can take to accelerate progress towards increasingly effective and transparent uses for health data.

**8:30 am**                      **Coffee and Light Breakfast Available**

**9:00 am**                      **Welcome, Introductions & Meeting Overview**

*Welcome from the National Academy of Medicine*

**Michael McGinnis**, National Academy of Medicine

*Opening remarks and meeting overview by Collaborative Co-chairs*

**Richard Platt**, Harvard University

**Richard Kuntz**, Medtronic



<b>9:30 am</b>	<b>Strategic Framing</b>  <b>Overview of the Leadership Consortium Operating Model and Principles</b>  <b>Michael McGinnis</b> , National Academy of Medicine  <b>Dashboard Indicators</b>  <b>Richard Platt</b> , Harvard University  <b>Richard Kuntz</b> , Medtronic
<b>10:45 am</b>	<b>Break</b>
<b>11:00 am</b>	<b>Rethinking Patient Data Privacy in the Era of Digital Health</b>  <i>In this session, participants will explore approaches to modernizing the regulatory framework for protecting health information.</i>  <b>Dan O'Neill</b> , RWJF Health Policy Fellow
<b>12:00 pm</b>	<b>Break To Pick Up Lunch</b>
<b>12:15 pm</b>	<b>Lunchtime Speaker: Consumer Behaviors in Other Sectors</b>  <i>In this session, participants will explore the landscape of consumer privacy and the implications for access and use of health data.</i>  <b>Linn Freedman</b> , Robinson & Cole
<b>1:15 pm</b>	<b>Break</b>
<b>1:30 pm</b>	<b>Emerging Technologies</b>  <i>In this session, participants will explore use of technologies used in other industries to ensure availability, security and transparency of sensitive data</i>  <b>John Halamka</b> , Mayo Clinic (remote) <b>Rob Califf</b> , Verily



**2:30 pm CERIC/EMAC Action: Opportunities for Collaborative Action**

*Participants will reflect on opportunities to improve data privacy, use, and access and expand EMAC portfolio of projects following the meeting.*

**Richard Platt**, Harvard University

**Richard Kuntz**, Medtronic

**3:00 pm Summary of Next Steps and Closing Remarks**

*In this session, Collaborative co-chairs will synthesize the day's discussion and offer participants a chance to state parting thoughts.*

**Richard Platt**, Harvard University

**Richard Kuntz**, Medtronic

**Michael McGinnis**, National Academy of Medicine

**3:30 pm Adjourn**