



*Collaboration for a Value & Science-Driven Learning Health System*

## National Academy of Medicine Leadership Consortium Digital Health Action Collaborative



February 20, 2020

Keck Center

Room 100

500 Fifth St NW | Washington, DC

**Meeting Focus:** An exploration of individual agency over health data as well as models for data sharing and principles for responsible data stewardship.

### Motivating Questions:

1. **Vision:** What conditions are needed to support patient-controlled data sharing for primary and secondary uses for both personal benefit and in support of a learning health system?
2. **Barriers:** What are the current societal/cultural, regulatory, organizational, and technical challenges to ensuring patient control over data sharing and availability of needed data for the learning health system?
3. **Use Cases:** What are best practices in data sharing and stewardship?
4. **Indicators of progress:** How do we evaluate success of patient-controlled data sharing in the context of a learning health system?

**Outcomes anticipated:** Identify actions NAM can take to accelerate progress towards increasing individual agency over health data sharing while ensuring access to data to support the learning health system.

**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*

**Jon Perlin**, Hospital Corporation of America

**Reed Tuckson**, Tuckson Health Connections, LLC



<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>Proposed Dashboard Indicators</b> <i>Co-Chairs</i>
	<b>Jon Perlin</b> , Hospital Corporation of America <b>Reed Tuckson</b> , Tuckson Health Connections, LLC
	<ol style="list-style-type: none"><li>1. Degree to which information about an individual is incorporated into the medical record and available to clinicians to support decision making to improve health</li><li>2. Percentage of provider organizations informing patients of use of their data</li><li>3. Percentage of provider organizations adopting patient access to provider notes</li><li>4. System-wide digital data accessibility for clinical care and research</li><li>5. EHR market penetration of AI to support CDS</li></ol>
<b>10:45 am</b>	<b>Break</b>
<b>11:00 am</b>	<b>Rethinking Health Data Ownership in the Era of Digital Health</b>
	In this session, participants will explore what constitutes health data ownership and individual agency over health information. <b>Amalio Telenti</b> , Vir Biotechnology Inc.
<b>12:00 pm</b>	<b>Break To Pick Up Lunch</b>
<b>12:15 pm</b>	<b>Lunchtime Speaker: Consumer Behavior</b>
	In this session, participants will explore models for patient-controlled data sharing in academic and commercial environments. <b>Lygeia Ricciardi</b> , Carium
<b>1:15 pm</b>	<b>Break</b>



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<b>1:30 pm</b>	<b>Best Practices from the Field</b>
	<p>In this session, participants will explore best practices in health data stewardship.</p> <p><b>Christopher Sealey</b>, Cover Us</p> <p><b>Kayte Spector-Bagdady</b>, University of Michigan, Center for Bioethics</p>
<b>2:30 pm</b>	<b>Digital Health Action Collaborative: Opportunities for Collaborative Action</b>
	<p>Participants will reflect on opportunities to advance and expand DHAC projects.</p>
<b>3:00 pm</b>	<b>Summary of Next Steps and Closing Remarks</b>
	<p>In this session, Collaborative co-chairs will synthesize the day's discussion and offer participants a chance to reflect on new opportunities to improve data use and access following the meeting.</p> <p><b>Michael McGinnis</b>, National Academy of Medicine</p>
<b>3:30 pm</b>	<b>Adjourn</b>

