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.

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<tr>
<th>Time</th>
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<tr>
<td>8:30 am</td>
<td>Coffee and Light Breakfast Available</td>
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<tr>
<td>9:00 am</td>
<td>Welcome, Introductions &amp; Meeting Overview</td>
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*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*
9:30 am  Strategic Framing

Overview of the Leadership Consortium Operating Model and Principles

Michael McGinnis, National Academy of Medicine

Proposed Dashboard Indicators

Co-Chairs

Jon Perlin, Hospital Corporation of America
Reed Tuckson, Tuckson Health Connections, LLC

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
2. Percentage of provider organizations informing patients of use of their data
3. Percentage of provider organizations adopting patient access to provider notes
4. System-wide digital data accessibility for clinical care and research
5. EHR market penetration of AI to support CDS

10:45 am  Break

11:00 am  Rethinking Health Data Ownership in the Era of Digital Health

In this session, participants will explore what constitutes health data ownership and individual agency over health information.

Amalio Telenti, Vir Biotechnology Inc.

12:00 pm  Break To Pick Up Lunch

12:15 pm  Lunchtime Speaker: Consumer Behavior

In this session, participants will explore models for patient-controlled data sharing in academic and commercial environments.

Lygeia Ricciardi, Carium

1:15 pm  Break
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<tr>
<th>Time</th>
<th>Session</th>
<th>Details</th>
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<tbody>
<tr>
<td>1:30 pm</td>
<td><strong>Best Practices from the Field</strong></td>
<td>In this session, participants will explore best practices in health data stewardship.</td>
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<tr>
<td></td>
<td><strong>Christopher Sealey</strong>, Cover Us</td>
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<td><strong>Kayte Spector-Bagdady</strong>, University of Michigan, Center for Bioethics</td>
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<td>2:30 pm</td>
<td><strong>Digital Health Action Collaborative: Opportunities for Collaborative Action</strong></td>
<td>Participants will reflect on opportunities to advance and expand DHAC projects.</td>
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<tr>
<td>3:00 pm</td>
<td><strong>Summary of Next Steps and Closing Remarks</strong></td>
<td>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.</td>
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<td></td>
<td><strong>Michael McGinnis</strong>, National Academy of Medicine</td>
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<tr>
<td>3:30 pm</td>
<td><strong>Adjourn</strong></td>
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