

NAM LEADERSHIP CONSORTIUM: Collaboration for a Value & Science -Driven Learning Health System
DIGITAL HEALTH ACTION COLLABORATIVE
February 20, 2020 Meeting Highlights

MEETING FOCUS: An exploration of individual agency over health data as well as models for data sharing and principles for responsible data stewardship.

REPRESENTATIVE OBSERVATIONS

Strategic Framing: Overview of the Leadership Consortium Operating Model and Principles

- x The meeting opened with a draft list of dashboard indicators that reflect the status of the field for measuring the nation's progress toward advancing population health.
- x Need to change indicators to reflect the current landscape of data sharing and responsible data stewardship.
- x Dilemma: We are pushing for having data from multiple sources but protections and rules are not apace with the rate of data creation and new business models
- x There is a need to figure out how to protect individuals without stifling free flow of information. This includes setting best practices for informing consumers of necessary disclosures and educating them on data protection laws and regulations. (Reed Tuckman, Co-Chair, Consortium)
Who holds and are using data pulled from a variety of sources. (Jane Hyatt Thorpe)
Need for transparency and meaningful choice for consumers in health care. Empowering individuals and organizations to understand what is being collected, tracked, and aggregated. (Dorothy Siemon)
Need to be transparent about how credit card transactions in granting access to data. Who do we trust with our healthcare data and how are they using it? When is it used? How to roll economic value of data back to patients? (Dale Sanders)
Need to focus on primary outcomes and sidestep privacy issues by embedding the analytics at the point of care. (Robert

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x There is a need for an industry

extent to which consumers understand and exercise their agency with regard to use of their health data for diverse purposes.

- x Catalog the changes in play with respect to digital health and health data and the fragmentation and constraints of the regulatory landscape.
- x Develop a consensus on consent and create template that is easy to understand and can be used by academia and industry alike.
- x Develop a trustworthy framework that can be applied to healthcare organizations about ways they collect and use data to build a trust environment .

MEETING PARTICIPANTS

NAM LEADERSHIP CONSORTIUM MEMBERS

Mark B. McClellan, Duke University (Chair)