Health Data & Consumer Agency: An Evolving Perspective

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02/ 20/ 2020

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What is health data?
A “Traditional” View of Health Data

Often data is by and for doctors, capturing a point in time and relevant episodic history.

The “Continuity of Care Record” (CCR) defines a set of core data elements that are most relevant and timely for treatment of an individual.

The legal record and “designated record set” defined by the HIPAA privacy rule typically include additional treatment and billing-related information relevant to an individual.

Core data elements generally include:

- Demographics
- Problems, diagnoses, conditions
- Treating practitioners’ names
- Allergies, reactions, risks
- Medications
- Lab reports (sometimes)
- Recommended care plan
An Evolving View of Health Data

Represents a holistic view of the life factors that influence health, revolves around the individual; some data is available continuously and in real time.

Data Source: Schroeder, NEJM
What agency can health data give individuals?
It Depends in Part on the Type of Access...

View Electronically

No Access/
No Knowledge/
Paper Only

Download/Share

Reuse and
Reinterpret via APIs
& Structured Data.
A “Traditional” View of Individual Agency via Health Data

Data access enables individuals to:

- Correct errors in the medical record
- Better understand their own health
- Better communicate with healthcare providers
- Remember details of a medical encounter and follow up appropriately
- Share with an expanded care team (formal & informal); be an “HIE of One”

Image Sources: HHS and OpenNotes
An Evolving View of Individual Agency via Health Data

Data access ALSO enables individuals to:

- Use apps and tools to meet their own health goals
- Share for profit, greater good (research), or peer support
- Predict and prevent illness
- Change health behaviors

Sources: Logos from their respective company websites.
Agency Example 1: Impact of Engagement on Health Outcomes

- **Hospital Readmit within 30 Days**
  - Most Activated Patient: 13%
  - Less Activated Patient: 28%

- **Experience Medical Error**
  - Most Activated Patient: 19%
  - Less Activated Patient: 36%

* People over 50 with 2+ health conditions

Data Source: AARP
Agency Example 2: Managing Chronic Disease

86% of the healthcare dollars we spend as a nation are on chronic disease

70%+ of deaths are due to chronic disease

Source: AMA
What is the contextual landscape for health data?
Health Data Volume is Expanding Exponentially

More data will be created this year than in the previous 5,000 years—and in health, that’s mostly “non-traditional” types.

Sources: Inhealth Record Systems, Greenway Health, PLOS, App Developer Magazine
The Number of Participants in the Health Ecosystem are Expanding

84% of the Fortune 50 are involved in healthcare, up from 76% in 2013

20% of consumers have been treated at a health clinic in a retail setting

Source: PwC
The Data Cow is Already Out of the Barn

Source: The DataMap, Latanya Sweeney
What are the implications for public and private sector policy?
The Consumer Has to be the CEO of their Own Health Data

- Know where it is
- Understand implications of use/sharing of data
- Choose or deny access to and use of it for particular purposes
- Have tools to leverage it for personal agency
Areas NAM Could Greatly Influence

- Support existing policy changes & enforcement
  - CMS/ONC rules regarding API access, data blocking
  - Progression to value based care
  - OCR enforcement of “right of access”

- Call for new comprehensive privacy policy legislation
  - HIPAA is too limited in whom it applies to, BA structure is complex
  - Rethink data “de-identification” standards

- Spearhead private-sector led activities
  - Develop tools and guidelines for consumer literacy, health quality and cost, privacy/data use
  - Example: Create model templates for privacy that are layered, consistent, and clear
Let’s do this, together!

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We’ll get there, together.