

Health Data & Consumer Agency: An Evolving Perspective

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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 screenshot shows a web-based interface titled "Personal Health Viewer" displaying a "Continuity Of Care Record" for a patient named John Quincy Doe. The record is organized into several sections:

- From:** Home Electronic Health Record
- To:** Doe, John Quincy
- Type:** Electronic Health Record
- Address:** 1010 Morris Road San Francisco, CA 94304
- Version:** Version 3.25 Beta
- Phone:** 415-555-1212
- Email:** johndoe@hcapordemo.com

Patient Detail:

- Name:** Doe, John Quincy
- Address:** 1010 Morris Road San Francisco, CA 94304
- Phone:** 415-555-1212
- Email:** johndoe@hcapordemo.com
- Date Of Birth:** 1917-03-14
- Gender:** Male
- Language:** English-Fluent
- Religion:** Catholic
- Race:** Caucasian
- EHealth:** InH

Problems, Diagnoses, and Conditions:

ICD9-CM	Condition	Code	Status
199-04	Congestive Heart Failure, Etiology - Benign Hypertensive Heart Disease	402.35	Active
194-03	Diabetes Mellitus, Type II (Adult Onset, Insulin-Dependent, Labile)	250.02	Active
Age 33	Hypertension, Benign, Etiology - Renal	403.10	Active
Occurrence 2003-01-25	Myocardial Infarction, Anter, Septal	410.80	Resolved
2002-03-25	Atrial Fibrillation	427.35	Chronic

Alerts, Adverse Reactions, and Allergies:

Description	Code	Reaction	Causative Agent	Date	Comment
Allergic Reaction	915.2	Anaphylactic, LifeThreatening	Penicillin	Initial Occurrence	
Allergic Reaction	915.2	Rash/Eruption, Mild	Sulfa	Initial Occurrence 2002-03	Patient states that he is unsure whether or not he really is allergic, as he was taking two new medications at the same time.

Image Source: CapMed & PSQH

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.

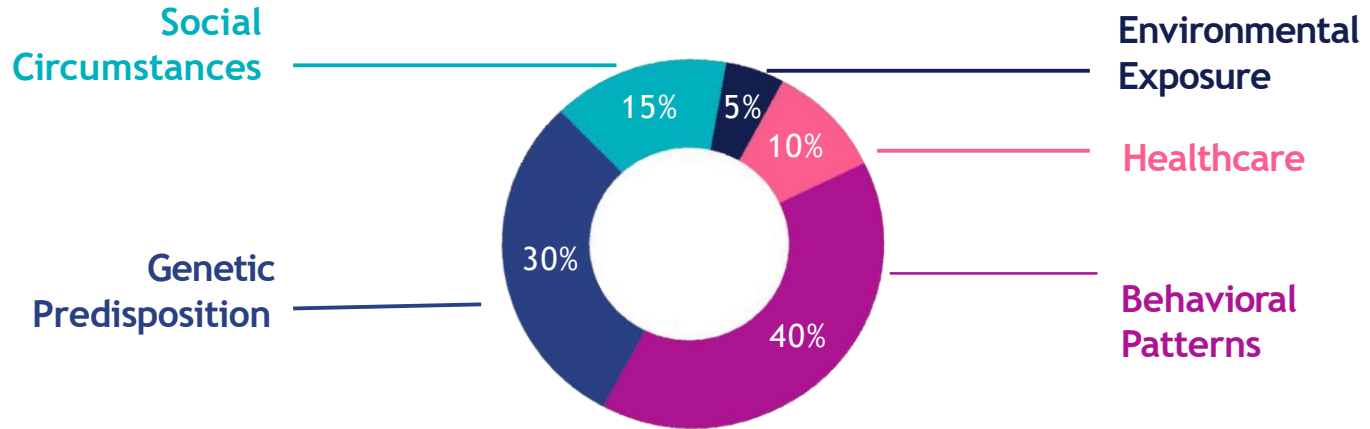
Core data elements generally include:

- 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”



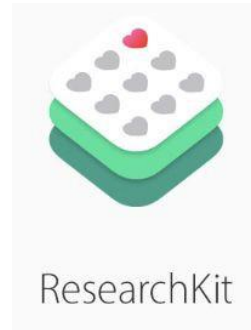
Image Sources: HHS and OpenNotes



An Evolving View of Individual Agency via Health Data

Data access ALSO enables individuals to:

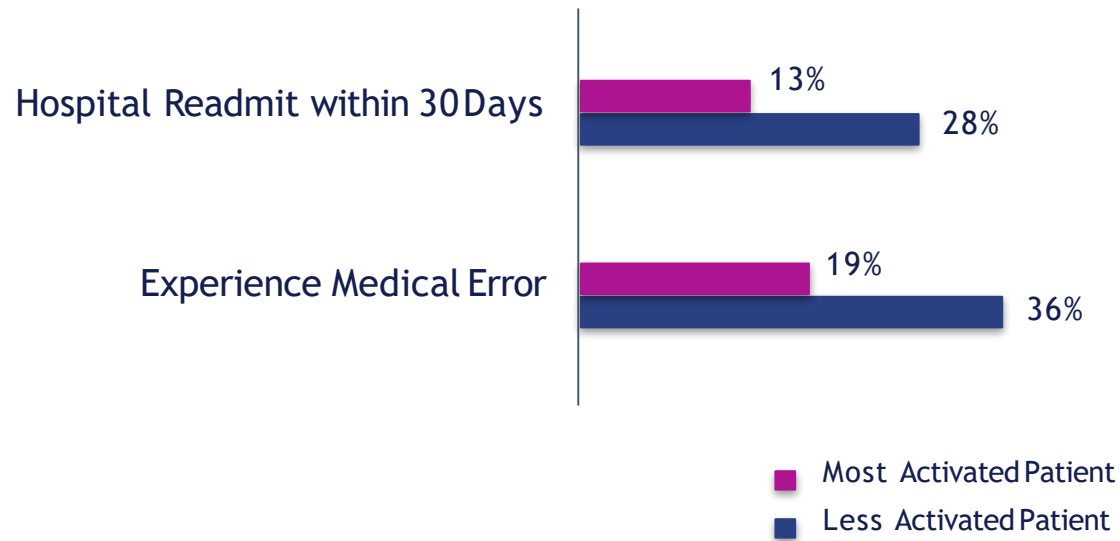
- Use apps and tools to meet their own health goals
- Share for profit, greater good (research), or peer support
- Predict and prevent illness
- Change health behaviors



Sources: Logos from their respective company websites. .



Agency Example 1: Impact of Engagement on Health Outcomes



* 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

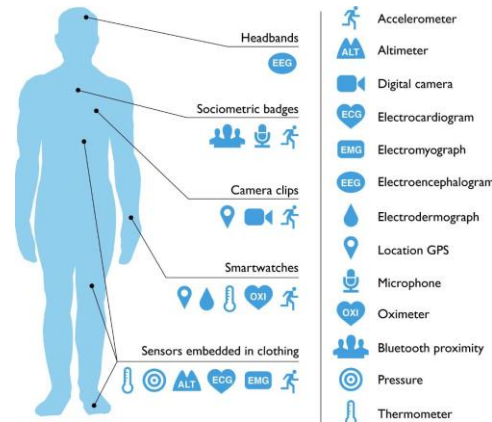


What is the contextual
landscape for health data?



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.



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



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.