Slide 1: Collaborating for Health: Engaging Community Intelligence for Better Patient Outcomes

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Slide 2: Emergence of the Participative Web

- Characteristics of new Web
    - Platforms for participation
    - Harnessing "collective intelligence"
    - Data as the new "Intel inside"

Slide 3: Evolution of Capabilities

Cartoon illustrating what happens when data is shared in new and innovative ways. The left panel shows effects of Web 1.0 and the left panel shows the effects of Web 2.0

Slide 4: "Groups applying knowledge to adapt to a changing environment."

- The concept is basic, historic. For example:
    - Collective behavior of bees, as influenced by communication within hives.
    - Libraries as technology for collecting community knowledge.

Slide 5: Massive connectivity changes the game

- Data collected from multiple, remote sources necessitate a global platform
- Example: Oceanographic data are collected from:
    - Shipboard instruments (e.g., research vessels; commercial ships; airplanes)
    - Unattended instruments (e.g., moored and drifting buoys)
    - Remote sensors (e.g., polar ice caps; equatorial Pacific)
    - Satellites

Slide 6: New Ways of Working Through Networks (1)

- Differential benefits of working online

Slide 7: New Ways of Working Through Networks (2)

- Social influences for being online
- Temporal asynchrony and synchrony
- One-to-many, many-to-many conversations
- Information support in "virtual communities"

Source: Eisenberg Center Conference Series 2010, The Prospect for Web 2.0 Technologies for Engagement, Communication and Dissemination in the Era of Patient-Centered Outcomes Research, Effective Health Care Program Web site (http://www.effectivehealthcare.ahrq.gov/index.cfm)

- Access to remote information resources
- Expansion from local to global
- Collective cognition: "Does anybody know?"

Slide 8: Public Innovations on Scientific Platforms (1)

- Framework for data mash-ups (Web application hybrid)
- User-generated content
- Google Earth

Slide 9: Public Innovations on Scientific Platforms (2)

- Science 2.0: mass participation in knowledge generation
- Participatory sensing

Slide 10: "Collective Intelligence" as the New Epistemology

For example, an open letter was addressed to President Obama in support o social participation (*Government Computer News*, August 3, 2009):

> *Unleash the power of "technology-mediated social participation" to solve the biggest problems facing the United States in the next century.*

Slide 11: Opportunities in Health and Health Care

1. "Crowd-sourcing" science
2. Mining the online information environment for observable patterns
3. Patients offering personal data in a disease-oriented commons
4. Predictor systems, collective polling, and basic use of the Internet
5. Sharing medical data for personal action and quality improvement
6. Data-enriched communities of health

Slide 12: "Crowdsourcing" Science–Public

- Benefits
    - Reinvigorate public interest in science
    - Overcome stumbling blocks to discovery (e.g., recruitment)
    - Improve "n"/power
- Tensions
    - Need to update sampling statistics
    - Coordination needed between advocacy groups and science
    - Quality control
    - No common vocabulary
    - Individual versus team incentives
    - Example: Army of Women (http://www.armyofwomen.org/)

Source: Eisenberg Center Conference Series 2010 Th Prospect for We 2.0 Technologies for Engagement, Communication and Dissemination in the Era of Patient-Centered Outcomes Research, Effective Health Care Program Web site (http://www.effectivehealthcare.ahrq.gov/index.cfm)

- Participation goal is million women
- 331,000 women have been enrolled since mid 2009

Slide 13: Mining the Online Information Environment for Observable Patterns

- Benefits
  - Gaining traction in private sector
  - Petabytes of data already exist
  - Observed, rather than self-reported
- Tensions
  - Lack of computing power in health
  - Resistance to data mining approach
  - Privacy issues
- Example: Infovigil (http://infovigil.com)
  - Developed by Gunther Eysenbach, M.D., M.P.H., in the Centre for Global eHealth Innovation at the University of Toronto
  - An infoveillance prototype

Slide 14: Patients Offering Personal Data in a Disease-Oriented Commons

- Benefits
  - Improves likelihood of detecting side effects
  - Permits social comparison
  - May facilitate self-regulation processes
- Tensions
  - Need to renegotiate boundaries between private sector, public sector, and citizens
  - New rules needed for rigor and control
- Example: PatientsLikeMe Web site (http://www.patientslikeme.com/)

Slide 15: Predictor Systems, Collective Polling, and Social Media (1)

- Necessary Conditions
  - Independence of opinion
  - Method to poll/record vote
  - Individual competency
  - Mutual goal
  - Diversity

Slide 16: Sharing Medical Data for Personal Action and Quality Improvement (1)

Source: Eisenberg Center Conference Series 2010 Th Prospect for We 2.0 Technologies for Engagement, Communication and Dissemination in the Era of Patient-Centered Outcomes Research, Effective Health Care Program Web site (http://www.effectivehealthcare.ahrq.gov/index.cfm)

"People often ask, 'If we give you your data, what are you going to do with it?' We don't know—that's the point: innovators haven't gotten their hands on it yet!"
—*Dave deBronkart, e-Patient Dave*

Slide 17: Sharing Medical Data for Personal Action and Quality Improvement (2)

- Benefits
    - "Many eyes" on record to improve quality
    - Memory cue for patient after exam
    - Personal right of patient
- Tensions
    - Is some information "toxic?"
    - Will doctors be unnecessarily restricted in what they write?

Slide 18: Data-Enriched Communities of Health

- Benefits
    - Data are public trust resource that should be given back to public
    - The right data should spur community improvement efforts
- Tensions
    - Do too many data lead to "data smog"
    - Format for delivery, usability largely untested
- Example: U.S. Department of Health and Human Services Community Health Data Initiative

Slide 19: The National Health Information Infrastructure (1)

Image of 3 intersecting circles titled: Healthcare Provider Dimension; Personal Health Dimension; and Population Health Dimension

Slide 20: The National Health Information Infrastructure (1)

Image of 6 arrows pointing to 3 intersecting circles.

- Two arrows point to the circle titled Healthcare Provider Dimension: Public Transparency, Physician Participation Sites
- Two arrows point to the circle titled Personal Health Dimension: Patient participation Sites
- Two arrows point to the circle titled Population Health Dimension: User-augmented Reality, Communities of Health

Source: Eisenberg Center Conference Series 2010, The Prospect for Web 2.0 Technologies for Engagement, Communication and Dissemination in the Era of Patient-Centered Outcomes Research, Effective Health Care Program Web site (http://www.effectivehealthcare.ahrq.gov/index.cfm)