Slide 1

SINI 2017
27th Summer Institute in Nursing Informatics
Clinical Practice, Health, and the Internet of Things
July 11-14, 2017
University of Maryland School of Nursing, Baltimore, MD

Comprehensive Electronic Patient Information When and Where Needed

William A. Yasnoff, MD, PhD, FACMI
Managing Partner, NHII Advisors
Adjunct Professor, Health Sciences Informatics, Johns Hopkins University

1

© 2017

Slide 2

William A. Yasnoff, MD, PhD

Disclosures

Commercial Interest
   None

No unlabeled/unapproved uses of drugs or products

2

© 2017

Slide 3

LEARNING OBJECTIVES

1. Describe the goals of health information technology
2. Explain the importance of information architecture in achieving the goals
3. Describe how patient-centric, patient-controlled record repositories can address all the requirements

3

© 2017

Slide 4

Outline

- Goals of Health Information Infrastructure (HII)
- HII Challenges
  - Trust (Privacy & Security)
  - Records (Standards & Cooperation)
  - Sustainability (Business Model)
- Health Record Banking Solution
- Protecting Repository Security
- Next Steps

4

© 2017

Slide 5

The Problem with Health Records

- In the hospital, patients have a unified chart with all their records
- Outpatient information gap
  - No "outpatient chart"
  - No "unified health record" containing comprehensive records from all sources
- Results: overtreatment, undertreatment, and medical errors
- 2015 patient survey re: doctor visits
  - 55% report medical history missing/incomplete
  - 49% report physician not aware of which prescription meds they're taking

5

© 2017

Slide 6

Why Now?

- Medical knowledge explosion → specialization → multiple providers → scattered records
- No provider has complete records → costs increasing, outcomes poor, errors too common
- EHR adoption increasing → new opportunities to manage records
- Need/desire to engage patients for population health, requiring access to comprehensive records
- Widespread availability of smart phones that facilitate access, control, and consumer engagement

6

© 2017

1

Case Study, Part 1

Diane, age 69

The Health IT Problem

- Comprehensive Electronic Patient Records When and Where Needed
  - Immediate access to comprehensive records for individuals (for care)
  - Ability to search and aggregate across population (for population health, quality improvement, medical research, and policy)
    - Does not require immediate response time

Health IT Requirements

- All patient records must be
  - Digital
  - Encoded with common standards
- Need mechanism for aggregation
  - Individual records created & stored at every site of care
  - Must be able to immediately access all records for a given individual

Architectural Approaches

- Federated (Distributed) Model
  - Leave records where they are created
  - Retrieve and aggregate records in real time when needed
- Centralized Model
  - Deposit records in a centralized repository
  - Each patient's records stored together in one "account"
  - Comprehensive records immediately available when needed

Federated (Distributed) Model

HIE

Clinician EHR → ① → Index → ②

Patient Encounter ④ Assembly ③ → Other EHRs

⑤
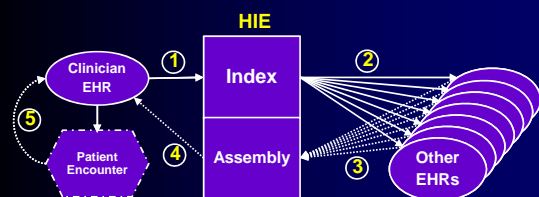
Diagram © Health Record Banking Alliance, 2013. Used by permission.

VIEWPOINT

JAMA, March 13, 2013—Vol 309, No. 10 **989**

Putting Health IT on the Path to Success

William A. Yasnoff, MD, PhD
Latanya Sweeney, PhD
Edward H. Shortliffe, MD, PhD

teed availability of comprehensive information from all sources.

One consequence of these failings is that HIT has yet to decrease health care costs; in fact, costs are increasing be-

Current Efforts are Failing

- HHS: Current efforts "alone will not be enough to achieve the widespread interoperability and electronic exchange of information necessary for delivery reform where information will routinely follow the patient regardless of where they receive care." -- ONC/CMS RFI 3/7/13, p. 5
- PCAST: HIE efforts through the states "will not solve the fundamental need for data to be universally accessed, integrated, and understood while also being protected." – Dec 2010, p. 40

© 2017

Current Efforts are Failing
(continued)

- Adler-Milstein *et al* HIE Survey (Annals of Internal Medicine, May 2011)
  - 179 HIEs surveyed
  - Only 13 met Meaningful Use Stage 1
    - 3% of hospitals, 0.9% of physicians
  - Only 6 of 13 self-reported as sustainable
  - None of 179 met expert panel definition of comprehensive system, calling "into question whether RHIOs* in their current form can be self-sustaining and effective." (abstract)

©*Regional Health Information Organizations
© 2017

Current Efforts are Failing
(continued)

- Multiple HIEs have already failed
  - Washington, DC
  - Kansas
  - Tennessee
  - CalRHIO
  - CareSpark (Kingsport, TN)
    - Long touted as national leader
- No patients currently receive care with guaranteed availability of comprehensive records from all sources

© 2017

Current Efforts are Failing
(continued)

- Why are HIEs failing?
  - Substantial resources: $564 million Federal funds allocated March 2010
  - Challenges well known
    - Trust
      - Privacy
      - Security
    - Obtaining Records
      - Stakeholder Cooperation
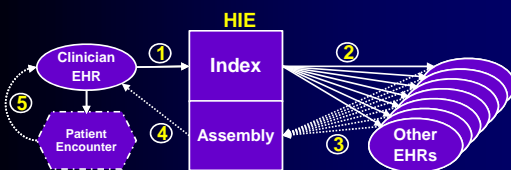   - Standards
    - Sustainability (Business Model)

© 2017

Current Efforts are Failing
(continued)

- What's the Root Cause?
  - Wrong Path
  - Trying to replicate manual process of contacting other providers directly for records

Diagram © Health Record Banking Alliance, 2013. Used by permission.

© 2017

---

Current Efforts Can't Work

- Complex and Expensive
  - All EHRs must be online 24/7 to respond to queries
  - Real-time reconciliation of records
  - Requires unique patient identifier
    - Politically impractical
    - Privacy threat
  - Must have expensive 24/7 network operations center to monitor all contributing EHRs

© 2017

Current Efforts Can't Work
(continued)

■ **Increasing Errors with More Data Sources**
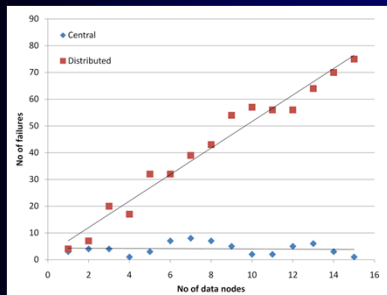
Source: Lapsia V, Lamb K, Yasnoff WA: Where should electronic records for patients be stored? *Int J Med Informatics* 81:821-827, 2012.
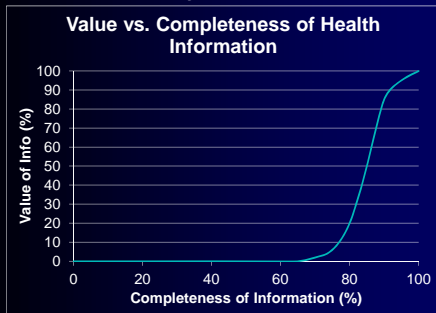
19   © 2017

Current Efforts Can't Work (continued)

■ **Increased Liability**
- ● **Patients cannot review or annotate data**
- ● **Providers and HIE responsible for correctness**
- ● **No propagation of corrections**

20   © 2017

Current Efforts Can't Work (continued)

■ **Not Financially Sustainable**

Value vs. Completeness of Health Information

Source: Yasnoff WA: Health Information Infrastructure. In *Biomedical Informatics: Computer Applications in Healthcare and Medicine*, Fourth Edition (Shortliffe & Cimino, eds.). New York: Springer-Verlag, 2014, pp. 423-441.

21   © 2017

Current Efforts Can't Work (continued)

■ **Unable to Protect Privacy**
- ● **Where can consumers indicate their privacy preferences?**
- ● **If data left at sources, consumers must set and maintain their preferences at every source → too complex and inconvenient**

22   © 2017

Current Efforts Can't Work (continued)

■ **Unable to Ensure Stakeholder Provision of Patient Information**
- ● **Stakeholder participation in HIE is voluntary**
  - – **Difficult to get cooperation**
  - – **Difficult to maintain cooperation**
- ● **Only patient requests for information must be honored by all stakeholders**

23   © 2017

Current Efforts Can't Work (continued)

■ **Unable to Facilitate Robust Data Searching**
- ● **Distributed records → slow sequential search**
- ● **Searching is critical to generating value**
  - – **Apps**
  - – **Research**

24   © 2017

4

Consequences for Stakeholders

Stakeholder	Problems
Health Plans/Insurers	1. Continually escalating costs 2. No comprehensive patient records
Hospitals/ACOs	1. Inadequate/incomplete patient information on admission and in ER 2. Uncontrollable financial risk (e.g. from readmissions) 3. Ineffective/inefficient prevention activities
Physicians	1. EHRs just "electronify" existing silo of patient records 2. No comprehensive patient records → better care 3. Ineffective/inefficient prevention activities
Patients	1. Preventable errors 2. Preventable adverse events 3. Unnecessary repeat tests/procedures 4. Continually escalating costs
Government/ Community	1. Continually escalating costs 2. Prevention efforts ineffective/underfunded 3. Data unavailable for policy & research

25

© 2017

HIT Architecture Choices

- Distributed architecture – does not work
  - Leave information in place; retrieve in real time when needed
  - Problems
    - Inefficient
    - Error prone
    - Does not scale
    - Hard to protect privacy
    - Impractical to search data
- Centralized architecture (health record banks)

26

© 2017

Solution:
Health Record Bank (HRB)

- Secure community-based repository of complete health records
- Access to records completely controlled by patients (or designee)
- "Electronic safe deposit boxes"
- Information about care deposited once when created
  - Required by HIPAA (in U.S.)
- Allows EHR incentives to physicians to make outpatient records electronic & ensure standards compliance
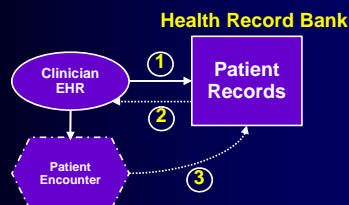- Operation simple and inexpensive

27

© 2017

What is a Health Record Bank?

http://videos.weebly.com/uploads/9/6/9/4/9694117/hrba-0001_363.mp4

28

© 2017

HRB Architecture

Health Record Bank

Clinician EHR → ① Patient Records
②
Patient Encounter ③

Diagram © Health Record Banking Alliance, 2013. Used by permission.

29

© 2017

HRB Rationale

- Operationally simple
  - Records immediately available
  - Deposit new records when created
  - Enables value-added services
  - Enables research queries
- Patient control ➡
  - Trust & privacy
  - Stakeholder cooperation (HIPAA)
- Low cost facilitates business model
- Creates EHR incentive options
  - Pay for deposits
  - Provide Internet-accessible EHRs

30

© 2017

HRB Enablers

- **Records are largely electronic**
- **Consumers have legal right to electronic copies of their records (HIPAA)**
- **Effective standards are available**
- **Patient portals & HIEs are data sources**
- **Smart phones are nearly ubiquitous allowing easy access, control, and consumer engagement**
- **New computer security methods prevent large-scale data breaches** ←

31   © 2017

HRB Security Challenge

- **Centralized data best way to ensure security***
  - **Distributed data less secure: multiple transmission for each use**
- **Inherent vulnerability of central database**
  - **Single point of access to all data**
  - **Potential loss of all data in one incident**
- **Multiple security breaches → widespread belief that nothing is secure**
  - **Perception is now reality**
- **Challenge: Efficient search without central database**

32   *Turn R, Shapiro NZ, Juncosa ML. Privacy and Security in Centralized vs. Decentralized Database Systems. *Policy Sciences* 1976;7:17-29.   © 2017

A secure and efficiently searchable health information architecture   CrossMark

William A. Yasnoff *

NHII Advisors, 1854 Clarendon Blvd., Arlington, VA 22201-2914, United States
Health Sciences Informatics, Johns Hopkins University, 2024 Monument St., Suite 1-200, Baltimore, MD 21205, United States
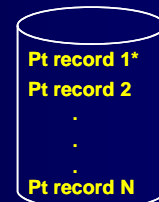
http://dx.doi.org/10.1016/j.jbi.2016.04.004

33   © 2017

Avoiding Total Data Loss

- **Each patient's data stored in central location**
  - **Separate file for each patient**
  - **Separate encryption**
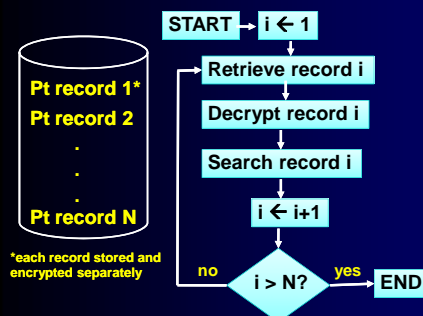- **Pro: no single point of access to all data**
- **Con: Sequential searching**

Pt record 1*
Pt record 2
.
.
.
Pt record N

*each record stored and encrypted separately

34   © 2017

Searching Separate Records

Pt record 1*
Pt record 2
.
.
.
Pt record N

*each record stored and encrypted separately

START → i ← 1
↓
Retrieve record i
↓
Decrypt record i
↓
Search record i
↓
i ← i+1
↓
no ← i > N? → yes → END

Requires N iterations

35   © 2017

Searching: 2 Processors

Pt record 1*
Pt record 2
.
.
.
Pt record N

*each record stored and encrypted separately

START → i ← 1
↓
Retrieve record i   Retrieve record i+1
↓   ↓
Decrypt record i   Decrypt record i+1
↓   ↓
Search record i   Search record i+1
↓
i ← i+2
↓
no ← i>(N-1)? → yes → END
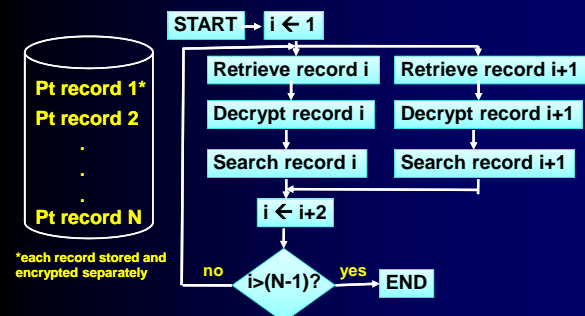
Requires N/2 iterations

36   © 2017

6

Searching: K Processors

START → i ← 1

Retrieve rec i	Retrieve rec i+1	. . .	Retrieve rec i+K-1
Decrypt rec i	Decrypt rec i+1	. . .	Decrypt rec i+K-1
Search rec i	Search rec i+1		Search rec i+K-1

i ← i+K

i>(N-K)? — no / yes → END

In cloud environment, K can be 1,000 or even 10,000 → fast searching

Requires N/K iterations
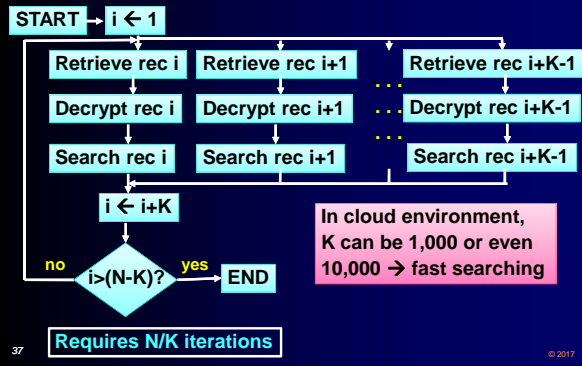
37 © 2017

Personal Grid Architecture

- **Each patient's record stored in separate file with separate encryption**
- **Efficient massively parallel searching using virtual processors in cloud and/or network (which may include mobile phones)**
- **No access point for all patients' data – even for operator of service**
  - **Eliminates "database in the sky" security vulnerability**

38 © 2017

Lessons Learned from a Health Record Bank Start-up
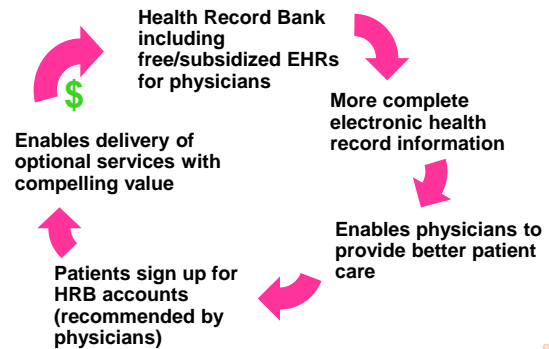
W. A. Yasnoff[1]; E. H. Shortliffe[2]

[1]President, Health Record Banking Alliance (Arlington, VA); Managing Partner, National Health Information Infrastructure (NHII) Advisors (Arlington, VA); Adjunct Professor, Division of Health Sciences Informatics, Johns Hopkins University (Baltimore, MD);
[2]Chair, Advisory Board, Health Record Banking Alliance (Arlington, VA); Professor and Senior Advisor, College of Health Solutions, Arizona State University (Phoenix, AZ); Adjunct Professor, Columbia University (Biomedical Informatics) and Weill Cornell Medical College (Division of Quality and Medical Informatics, Department of Public Health); Scholar in Residence, New York Academy of Medicine (New York, NY)

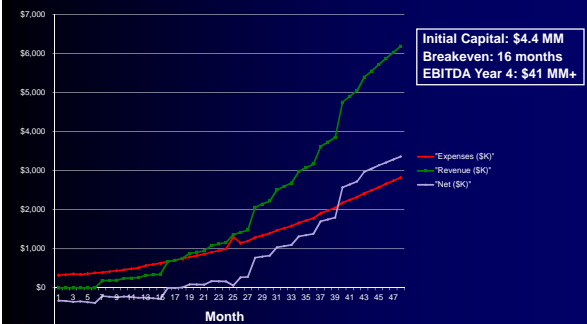39 © 2017

How HRBs Create Value

Health Record Bank including free/subsidized EHRs for physicians

$

More complete electronic health record information

Enables delivery of optional services with compelling value

Enables physicians to provide better patient care

Patients sign up for HRB accounts (recommended by physicians)

© 2017

HRB Business Model

- **Costs (with 1,000,000 subscribers)**
  - **Operations: $6/person/year**
  - **EHR incentives: $10/person/year**
- **Revenue**
  - **Sponsorships: ~$3/person/year**
  - **Reminders & Alerts: >= $18/person/year**
    - **"Peace of mind" alerts**
    - **Preventive care reminders**
    - **Medication reminders**
  - **Queries: >$3/person/year**
- **No need to assume/capture any health care cost savings (!!)**

41 © 2017

Pro Forma Example (Houston)

Initial Capital: $4.4 MM
Breakeven: 16 months
EBITDA Year 4: $41 MM+

"Expenses ($K)"
"Revenue ($K)"
"Net ($K)"

Month

42 © 2017

7

Case Study, Part 2

Diane, age 69

43

© 2017

Next Steps

- Implement Health Record Bank Pilots
  - Looking for candidate communities
  - Need outside funding to reduce risk
- Disseminate Lessons Learned
- Organize Health Record Bank Projects in Multiple Communities

44

© 2017

SUMMARY

- HII Requires Comprehensive Patient-centric Records
  - Individual care
  - Searchable for population health, quality improvement, medical research, and policy
- Health Record Banks Create Effective HII
  - Incentives for EHR Adoption/Standards
  - Security and Privacy
  - Excess Revenue
- Need Implementation of Community HRBs for Successful HII

45

© 2017

Questions?

William A. Yasnoff, MD, PhD, FACMI
william.yasnoff@nhiiadvisors.com
703/527-5678

46

© 2017