

# No Records About Me Without Me

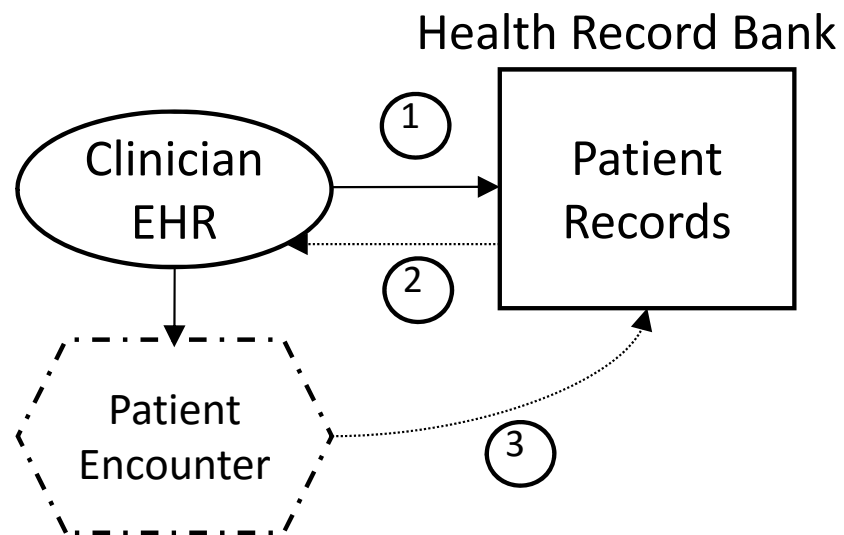
Richard Gibson MD

Executive Director

Health Record Banking Alliance

AMDIS – Ojai CA - Thursday, 22 June 2017

# Health Record Bank



# It's not your grandmother's Personal Health Record



- Journaling data input by the consumer
- Consumer had to collect the data
- Little EHR content available
- Providers couldn't rely on the documents



## Modern PHRs = Health Record Banks

- Limited data entry by consumer
- EHRs now have standard data output
- Chance for automated data updates
- Best PHRs keep provider data unaltered
- Ability to reconcile data inputs
- Ability to collect diagnostic images



HIEs	HRBs
Many-to-many scattered distribution	One-to-one sending of record
Difficult to reconcile multiple copies of data elements on the fly (federated model) and done multiple times	Able to scale record reconciliation from multiple providers and done just once
No persistent record (HIEs without repository)	Persistent record
Requires broad governance among multiple stakeholders	Requires a trusted repository organization
Perceived as the Providers' Record	Perceived as the Consumer's Copy of the Providers' Record
Genomic and imaging data scattered across many sources	A copy of all genomic and imaging data in one place

HIEs	HRBs
Less helpful when consumer moves geographically	No change: new providers continue to add to the single record
Difficult for consumer to chose apps to run against data	Ideal setting for consumer to choose apps to run against their comprehensive data
Difficult to correct a distributed error	Correct error in just one place
Difficult for consumer to control access	Easy for consumer to control access
Consumer uploads device & entered data to multiple EHRs	Consumer uploads device & entered data to one account



## HIPAA is Clear on Consumers Receiving Their Record

For the individual:

“Where an individual requests an electronic copy of PHI that a covered entity maintains electronically, **the covered entity must provide the individual with access to the information in the requested electronic form and format**, if it is readily producible in that form and format.”

For the individual’s designated trustee:

“An individual also has a right to direct the covered entity to **transmit the PHI about the individual directly to another person or entity** designated by the individual.”



Source: Individuals’ right under HIPAA to access their health information. 45 CFR § 164.524. Washington, DC: Office for Civil Rights, Department of Health and Human Services; 2016. <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/index.html>.



Sec 4006: “The Secretary shall use existing authorities to encourage partnerships between health information exchange organizations and networks and health care providers, health plans, and other appropriate entities with the goal of offering patients **access to their electronic health information in a single, longitudinal format** that is easy to understand, secure, and may be updated automatically.”

“The Secretary, in consultation with the National Coordinator, shall promote policies that ensure that a patient’s **electronic health information is accessible to that patient and the patient’s designees**, in a manner that facilitates communication with the patient’s health care providers and other individuals, including researchers, consistent with such patient’s consent.”



## Personal health record systems have some things in common

- Available on mobile phones
- Viewable via a browser
- Permission required for others to view data
- Providers either get a file or they can log onto provider viewer



From [holidogs.com](http://holidogs.com)



## Getting the Data Into the Repository

- Direct message (push)
- Scraping patient portals
- Provider offices receive email or Direct message to upload data to secure URL
- Sequoia/Commonwell/Carequality (query and retrieve)
- Fax → Optical character recognition → NLP → Human review
- FHIR API (in the future)
- Direct protocol + FHIR (query and retrieve) (in the future)

# Data types accepted



Continuity of Care Document (CCD®)

CCD® to Blue Button Transformation Tool



Blue Button Download My Data



Device data



jpg  
gif



Personal app data

From commons.wikimedia, freepik.com, Amazon.com, bhphotovideo.com, radiopaedia.org, Channeleyes.com, walmart.com, hellohealth.com

## Patient Identification

- just Username and Password
- Direct address, but only Level of Assurance (LoA) 1 (NATE): just username & password
- Some firms use Direct address, but require LoA 3 (DirectTrust)
  - Mailing address (for confirmation) or
  - Two factor authentication
    - Mobile phone response
    - Email response
  - Driver's license
  - Credit card
- Some providers fear reputational harm if they send data to LoA1 firms



From funjaki.com

## Firms differ in their use of Direct addressing for consumers

- Half the firms don't get Direct addresses
- Some firms get Direct address for firm, then sort the incoming data
- Some firms give consumers addresses at LoA1
- Some firms give consumers addresses at LoA3



From commons.wikimedia.org



Got Purpose?

START

Firms have widely differing purposes

- Pure PHR play
- Collecting data for life insurance companies
- Part of a care management platform
- As a byproduct of providing a data exchange platform

From [blog.dansplan.com](http://blog.dansplan.com)

## Firms differ in who is the primary buyer

- The consumer himself or herself
- Health system or provider group
- Health insurance company or ACO
- Care management companies
- Life insurance company
- Large employer
- A company willing to monetize the data for the consumer (with their permission)



# Adoptior

Cost/yr  
\$400  
\$130  
\$72  
\$0



<100



xMD  
nsumers  
cost



300k # of consumers



## PHRs differ somewhat in control of data



- All require consumer authorization for others to see
- Variable control at level of:
  - Section level: Meds, Fam History, etc
  - Data element level: a given med
- Variable ability:
  - Who accessed my record
  - Provide access to family member
  - Provide automatic access to emergency personnel

## Paying for a health record bank

- Insurance company or accountable care organization
- Large employer
- Monetization of data for research
- Commercial firms pay for access to data
- Consumer purchases apps to run against data



From: us-cash.info

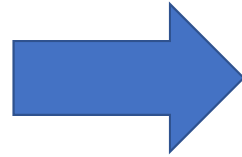
## Challenges of health record banks / personal health records

- No demand
  - Many consumers don't care about data
  - No killer app yet
  - PHRs haven't been done well yet
  - Consumers unaware of right of access
- Limited data from EHR still
- Providers unaware of obligation
- No clear business model
- Providers don't want another distraction
- Providers may not want to share data



## Our Request of ONC

Replace 917 pages of the Federal Register dealing with Meaningful Use and EHR Certification



- Provider required to notify patient
- Provider asks for patient's destination
- Use all 12 C-CDA document templates



Questions?

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