Personal Health Records
Their Benefits and the Role of Standards

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What is a PHR?

- ASTM E31.26 Draft Definition:

The Personal (Consumer) Health Record is an electronic application through which individuals can maintain and manage their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment that allows the individual or other authorized persons to access and share such information.

- Any system that enables patients to view or manage their own health information can be considered a PHR.

Who wants them, and who is providing them?

- A majority of patients express an interest in having a Personal Health Record.
  - First Consulting Group, "Personal Health Records" Summer, 2000
- Many organizations are providing PHR applications directly to patients:
  - Drug Stores & PBMs (Medication profile management)
  - Health Plans (Claims viewing)
  - Doctors (Sharing of electronic medical records, secure messaging)
  - Employers (Health and benefit management)
- Many vendors are supplying these organizations with the tools they need, many are building it themselves

What standards have been / should be discussed?

- Minimum Data Sets to facilitate data sharing
- Interoperability between electronic systems
- Patient Control and Privacy Standards
- Authentication Standards
- Consumer Terminologies to facilitate ease of use

What is the Goal?

Enabling patients to aggregate, integrate and share data across multiple providers and multiple systems enables greater consumerism resulting in greater cost management and health self-management, as well as enabling critical information to be available at the point of care.

We need a way to incent / encourage the systems and organizations that hold patient health data to share basic data elements electronically and securely with other systems of the patient's choice?

How to Achieve this Goal

- Define a Minimum Data Set
- Define a simple way in which minimum data set data can be shared between systems
- Ensure that privacy safeguards are applied to these systems
- Address the challenges of system authentication and individual authentication
- Incent/Encourage organizations to share the data with consumer-driven systems

PHR Minimum Data Sets – The Foundation of Portability

A minimum PII data set accessible by patients could ensure that the minimum amount of data is available to guide care decisions, cost prediction, and self management.

- Demographic Information
- Insurance and Provider Information
- Contact Information
- Current Conditions (condition, provider, date diagnosed, severity)
- Current Medications (med, dose, frequency, prescriber, date prescribed)
- Pertinent Test Results (test, date, results, trends, measurer)
- Allergies
- Immunization History
- Surgical History
- Current Health Risks and Family History

Many systems hold minimum data set data, but how will patients get access?

- Should all systems that hold such data be required to allow patients to view the data electronically?
  - No. Difficult to implement (UI, authentication challenges)
- Should all systems that hold such data enable patients to download the data electronically?
  - Yes, but download to what?
    - Smart Cards? - require readers
    - Web-based applications? – readily available

System Interoperability

• HL7 and HCFA CMS Forms are not focused on easing the exchange of patient-viewable data

• XML is becoming the default mechanism for data sharing, but the "content" of the exchange must still be defined

Interoperability – The Need to Standardize

- Standardization of electronic interfaces for sharing minimum data set data will…
    1. Enable patients to use PHR applications to aggregate and integrate their information
    2. Enable patients to share the data they wish to share with others
- A simple XML interface for the minimum data set would be easy for almost any system to implement
- Only needs to accommodate approximately 50 data types

Interoperability – The Authentication Challenge

- ## System-level validation
  - How does one system know that the other system requesting data is valid?
    - System Certificates
  - Recognize accredited, "authorized" PHR systems
- ## Individual-level validation
  - How does an "authorized" PHR system know that the person asking to gather data is valid?
    - Authenticated by a trusted entity (health plan, employer, hospital, doctor's office), or through a notarized certificate
  - How does one system get the right patient's data from the other system?
    - A National Identifier or a Master Person Index (MPI)?

Patient Control, Privacy and Authorization Standards: Do we need anything new?

- HIPAA and privacy groups (e.g. HIEthics) provide a general expectation for protecting privacy (the "floor")

- Standards for Authorization /Permission will become increasingly important
  - Systems that maintain patient-viewable data should comply with baseline permissions standards (e.g. A patient should be able to withhold data that they consider sensitive, or enable read-only access)
  - "Sensitive" data is different for every patient, so enabling patients to establish item-by-item permissions is important

- Audit Trail information standards applied to all systems that maintain patient viewable data would support privacy
  - "Who accessed or edited what data when?"

RECOMMENDATIONS

1. Establish a minimum data set, and through incentives support and encourage that all systems collecting any data in the data set must be able to share that data with other valid PHR systems of the patient's choosing.

   – Gives patients a mechanism for aggregating and integrating basic data across multiple systems

2. Support simple XML interface specifications for exchange of minimum data set data

3. In lieu of a national identifier, establish minimum MPI requirements for matching data to an individual

4. Establish minimum requirements for individual-level authentication (e.g. certificates)

5. Support accreditation of PHR systems to enable their access to other systems

   – Accreditation should require compliance with privacy, authentication, MPI, permissions and audit trail standards.

6. Support the wide-scale use of the patient's minimum data set

   – Support Emergency Room web access

Reference Slide 1- Key Features of a PHR

- Data
  - Structured Data
    - Conditions, Medications, Allergies, Test Results, Health Risks, Surgeries, Symptoms, Clinical Findings, Care Plans, etc
  - Unstructured Data
    - Journal entries, feedback about care, unstructured messages
- Patient-Centric Portability and Shareability
  - Emergency Record Summaries
  - Paper, Fax, Electronic, Phone, Smart Card integration
  - Interoperability with electronic data with other systems
- Other Bundled Features
  - Secure Messaging
  - Automated Feedback
  - Faxable, Printable Reports
  - Health Risk Assessments and Health Behavior Programs

Reference Slide 2 - Consumer Terminologies

- True "Interface" Terminologies
  - Provide the ability to interface patients to complex terms and concepts at a specified reading level
  - Provide the ability to translate colloquialisms and common phrases into medically-valid concepts
- Examples
  - WellMed's Consumer Health Terminology (CHT)
  - IMO's Personal Health Terminology (PHT)

Reference Slide 3 – a consumer terminology case study: WellMed's CHT

- Created in 1998
- Provides an interface for consumers to complex codes (contains consumer preferred terms to all 12,000 ICD9 codes and 14000 SNOMED codes
  - Example: "Diabetes Mellitus with ophthalmic manifestations" translated to "Diabetes with eye problems"
- Translates slang phrases like "water on the knee" to "knee bursitis"
- Includes coverage of over 30,000 unique concepts
- Problem 1 – Over-Engineering
  - Example: "Acute Gingivitis" translates into "Short Term Inflamed Gums"
- Problem 2 – Granularity
  - Example: Translating ICD9 code 250.00 "type II diabetes mellitus or unspecified type, not stated as uncontrolled, without mention of complication" to "Adult Onset Diabetes" is not an exact semantic match… how precise do we need to be in communicating to patients?