Facilitating Consumer Health: Technical Challenges in the Implementation of the Personal Health Record

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PHRs: Standards and KR

• PHRs
  – Why do we need them?
  – What are they?

• Making Use of PHRs: Clinical Decision Support?
  – Infobuttons
  – Guideline KR formalisms
Need for EHR = CDSS: Medical Errors

**Estimated annual mortality**

- Air travel deaths: 300
- AIDS: 16,500
- Breast cancer: 43,000
- Highway fatalities: 43,500
- Preventable medical errors: 44,000 -
  
  *(1 jet crash/day)* 98,000

**Costs of Preventable Medical Errors:**

*$29 billion/year overall*

Need for EHR/CDSS: Evidence of Poor Performance

• **USA:** Only 54.9% of adults receive recommended care for typical conditions
  – community-acquired pneumonia: 39%
  – asthma: 53.5%
  – hypertension: 64.9%


• **Delay in adoption:** 10+ years for adoption of thrombolytic therapy

Examples of EHR/CDSS Effectiveness

- **Reminders of Redundant Test Ordering**
  - *intervention*: reminder of recent lab result
  - *result*: reduction in hospital charges (13%)
    

- **CPOE Implementation**
  - Population: hospitalized patients over 4 years
  - Non-missed-dose medication error rate fell 81%
  - Potentially injurious errors fell 86%
    
Examples (continued)

- **Systematic review**
  - 68 studies
  - 66% of 65 studies showed benefit on physician performance
    - 9/15 drug dosing
    - 1/5 diagnostic aids
    - 14/19 preventive care
    - 19/26 other
  - 6/14 studies showed benefit on patient outcome

Need for Decision Support: Questions, Questions

- **Information needs**: Fulfilled; Unfulfilled but recognized; Unrecognized
  - **Need**: user-initiated support + “push” technology

- **Questions during clinical care**
  - N = 90 patients, 24 physicians
  - Avg 5 questions/patient
    - 52% = fact about patient
    - 48% = medical knowledge or synthesis with patient data

Characterizing the Record: Representing the Patient’s True State

True State of Patient

Diagnostic study

Clinician

Paper chart

Data entry clerk

Dictation

Transcription

EMR/Chart Representation

Hogan, Wagner. JAMIA 1997;4:342-55
Functional Components

- Integration of data
  - Standards: Messaging (HL7), terminology (LOINC, SNOMED, ICD9, etc), data model (HL7 RIM)
  - Interface engine

- Clinical decision support

- Order entry

- Knowledge sources

- Communication support: Multidisciplinary, consultation
Welcome to HealthVault

Be well. Protected.

Microsoft® HealthVault™ is designed to put you in control of your health information. A free HealthVault account helps you collect, store and share information with family members and gives you a choice of applications and devices to help manage your fitness, diet and health. Here's how it works.

New from HealthVault

The Microsoft HealthVault Be Well Fund will support innovative new online health applications. Get details.

See how hospitals will be able to connect with HealthVault in the future.

Web sites and programs that work with HealthVault

From the American Heart Association and American Stroke Association
Blood Pressure Management Center
Learn more

From CapMed
ICE: In Case of Emergency
Learn more

From MySelfHelp
MySelfHelp.com
Learn more

From HealthVault
HealthVault Connection Center
Learn more

From Healthy Circles
Healthy Circles
Learn more

Our Health Privacy Commitment

1. The Microsoft HealthVault record you create is controlled by you.
2. You decide what goes into your HealthVault record.
3. You decide who can see and use your information on a case-by-case basis.
4. We do not use your health information for commercial purposes unless we ask and you clearly tell us we may.

Read our full Privacy Statement.

Devices that work with HealthVault

From LifeScan, Inc.
Blood glucose monitors
Learn more

From Microlife
Blood pressure monitors
Learn more
Peakflow meters
Learn more

Done
PHRs and Consumer Attitudes

• **California Healthcare Foundation report based on Manhattan Research work in 2006/2007**
• **N = 1008**
• **Average age = 46**
• **Sample distribution**
  – 20% foreign born
  – **Age:** 45-54 (26%), 25-34 (24%)
  – **Formal Education:** 27% high school, 24% some college, 22% college degree

Sources of Health/Medical Information, California, 2007

- Internet: 45%
- Books, magazines, or newspapers: 41%
- Television: 29%
- Radio: 16%
Health-Related Activities Online, California, 2007

- Read health-related news articles: 67%
- Searched for condition- or disease-specific information: 67%
- Searched for general health information: 63%
- Used a health plan/insurer Web site: 40%
- Searched for prescription drug information: 38%
- Received health-related newsletters by email: 31%
- Used a hospital Web site: 21%
- Purchased a health-related product: 20%
- Used a doctor's/doctor's office Web site: 19%
- Sent email to health care professionals: 16%
- Participated in online support groups, chat rooms, or message boards: 10%
Interest in Accessing PHRs* Online,
California, 2007

- Not at all interested: 57%
- Already use: 2%
- Very/somewhat interested: 40%
Among Non-Users of Health Information Technologies, Activities That Elicit Security/Confidentiality Concerns, California, 2007

- Accessing personal health records: 39%
- Storing personal information on electronic health card: 37%
- Accessing lab test results: 33%
Contributing or Posting Health Content Online, California, 2007

“I regularly contribute or post health content online.”

- Strongly disagree: 35%
- Disagree: 51%
- Agree: 11%
- Strongly agree: 2%
- Don’t know: 1%
Summary: Need for PHR / EHR / CDSS

• **Medical errors are costly**
  – Charges/Costs
  – Morbidity/Mortality
• **CDSS technology can help reduce**
  – errors
  – costs
• **EHR**
  – Collection and organization of data
  – Vehicle for decision support
• **Consumers:** Provide personal data, manage health care
Evolving Definitions

• **Computer-based Patient Record (CPR):** Electronic documentation of care, integrating data from multiple sources (clinical, demographic info)
  - **EMR:** Single computer application for recording and viewing data related to patient care, typically ambulatory
  - **EHR:** Suite of applications for recording, organizing and viewing clinical data
    • Ancillary systems, clinical data repository, results review, “CIS”, “HIS”
  - “Record” (patient data) vs “Record System” (computer application containing patient data)
EHR = EMR + PHR + CPOE + (etc)

- **EMR**: A computer-accessible resource of medical and administrative information available on an individual collected from and accessible by providers involved in the individual’s care within a single care setting.

- **EHR**: A computer-accessible, interoperable resource of clinical and administrative information pertinent to the health of an individual. Information drawn from multiple clinical and administrative sources is used primarily by a broad spectrum of clinical personnel involved in the individual’s care, enabling them to deliver and coordinate care and promote wellness.

ONC Terms Standardization Project, Defining Key Health IT Terms, Interim Draft Report, 21 February 2008
Personal Health Record

• **PHR:** A computer-accessible, interoperable resource of pertinent health information on an individual. Individuals manage and determine the rights to the access, use, and control of the information. The information originates from multiple sources and is used by individuals and their authorized clinical and wellness professionals to help guide and make health decisions.

• **Recent Examples:** Microsoft HealthVault, Google Health, embedded patient portals (Centricity), Pre-Key (CSMC OB/GYN)

ONC Terms Standardization Project, Defining Key Health IT Terms, Interim Draft Report, 21 February 2008
Access to Knowledge: Infobuttons

- **Infobutton**: Application that mediates queries of knowledge sources by clinical applications (EHRs, etc)

- **Process**
  - Clinical information system invokes infobutton manager (IM) with patient/user data
  - IM creates 1+ infobuttons, each = different kind of query
  - User chooses infobutton to execute query against a knowledge source, which displays response

Cimino JJ, Li J, Bakken S, Patel VL. Theoretical, empirical and practical approaches to resolving the unmet information needs of clinical information system users. Proc AMIA Symp 2002::170-174.
Select context that applies:

- positive

Normal | Negative
--- | ---

Positive results are reported as +, ++, +++

- Ascorbic acid in urine can cause false-negative result
- Oxidizing agents (eg, iodides, bromide) can cause false-positive results.

References


Kaplan LA, Pesce AJ. Clinical chemistry: Theory.
### Pharmacy Medication List as of 8/26/2004 02:00

PMCC Allergy Information as of 8/25/04: **TETRACYCLINE**

#### Scheduled Medications

<table>
<thead>
<tr>
<th>Start Date</th>
<th>Medication</th>
<th>Dose (Click for More Info)</th>
<th>Stop Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>8/26/04</td>
<td>CYCLOPENTRAZEPINE (FLEXERIL)</td>
<td>2.5MG PO TID</td>
<td></td>
</tr>
<tr>
<td>8/26/04</td>
<td>SODIUM CHLORIDE 0.9% (HEP-Lock)</td>
<td>2CC IV PUSH QSJR</td>
<td></td>
</tr>
</tbody>
</table>

#### PRN Medications

<table>
<thead>
<tr>
<th>Start Date</th>
<th>Medication</th>
<th>Dose (Click for More Info)</th>
<th>Stop Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>8/25/04</td>
<td>ACETAMINOPHEN EXTRAS (TYLENOL EXTRASTRENGTH)</td>
<td>100MG PO OD PRN MODERATE PAIN</td>
<td></td>
</tr>
<tr>
<td>8/25/04</td>
<td>DEX (DIZAL)</td>
<td>100MG PO CE P 3/4 PRN CONSTITUTION</td>
<td></td>
</tr>
<tr>
<td>8/25/04</td>
<td>HYDROXYPHEN (OILAUD 200)</td>
<td>2MG IV PUSH QSJR PRN SEVERE PAIN</td>
<td></td>
</tr>
<tr>
<td>8/25/04</td>
<td>MECLOMORPHINE (ERGLAN)</td>
<td>10MG IV PUSH QSJR PRN NAUSEA</td>
<td></td>
</tr>
<tr>
<td>8/25/04</td>
<td>ONDANSETRON</td>
<td>2MG IV PUSH QSJR PRN NAUSEA COMING</td>
<td></td>
</tr>
</tbody>
</table>

Note: Click medication name for detailed dosage and administration information. Click **( )** for an online search of information resources.
Pharmacy Medication List as of 8/26/2004 02:00

MICROMEDEX(R) Healthcare Series - Microsoft Internet Explorer

MICROMEDEX(R) Healthcare Series Integrated Index

Terms Matched (CYCLOBENZAPRINE;)

- Summary Documents
  - Drug Summary Information [CYCLOBENZAPRINE HYDROCHLORIDE - Drug Summary Information]

- Drug Information
  - DRUGDEX DRUG EVALUATIONS [15 Related Occurrences]
  - Ingredients from DRUGDEX Tradename Products [CYCLOBENZAPRINE - Drug Evaluation]
  - PHYSICIANS' DESK REFERENCE [2 Related Occurrences]
  - MARTINDALE - The Complete Drug Reference [6 Related Occurrences]
  - MSDS [CYCLOBENZAPRINE HYDROCHLORIDE]
  - List of DRUGDEX® Tradename Products
  - List of MARTINDALE Tradename Products

- Disease Information
  - DISEASEDEX(TM) Emergency Medical Abstracts: Rick Fukata MD, Jerry Hoffman MD [3 Related Occurrences]
  - DISEASEDEX(TM) Emergency Medicine Clinical Reviews LOW BACK PAIN - therapy (a)

- Toxicology Information
  - PSYCHOPHARMACOCHEMICALS [CYCLOBENZAPRINE - Poisoning]
Drug Database Results:

Query: hydromorphone has produced 8 hits.

A to Z Drug Facts: 1
(Handy quick reference for drug information)

Drug Facts and Comparisons®: 6
(Comprehensive Drug Information)

FDA MedWatch: 1
(Alerts issued by the FDA)

Review of Natural Products: 0
(Quick reference for natural drug information)
### Infobutton Use by Knowledge Source: CSMC

<table>
<thead>
<tr>
<th>Source</th>
<th>Accesses</th>
<th>Time Period (mo)</th>
<th>Avg/Month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>58130</td>
<td>31</td>
<td>1876</td>
</tr>
<tr>
<td>Literature/Textbook</td>
<td>3906</td>
<td>28</td>
<td>139</td>
</tr>
<tr>
<td>Lab</td>
<td>3583</td>
<td>46</td>
<td>77</td>
</tr>
</tbody>
</table>
## Infobutton Use by Time: CSMC

<table>
<thead>
<tr>
<th>Period</th>
<th>Medication</th>
<th>Literature</th>
<th>Lab</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>10/2004</td>
<td>1347</td>
<td>146</td>
<td>335</td>
<td>1828</td>
</tr>
<tr>
<td>10/2005</td>
<td>2407</td>
<td>127</td>
<td>372</td>
<td>2906</td>
</tr>
<tr>
<td>10/2006</td>
<td>2870</td>
<td>215</td>
<td>378</td>
<td>3463</td>
</tr>
</tbody>
</table>
Web/VS Logins and Documents Viewed Per Month

Number of Logins:
- 0
- 100,000
- 200,000
- 300,000
- 400,000
- 500,000
- 600,000
- 700,000
- 800,000
- 900,000
- 1,000,000
- 1,100,000
- 1,200,000
- 1,300,000
- 1,400,000
- 1,500,000
- 1,600,000
- 1,700,000
- 1,800,000
- 1,900,000
- 2,000,000
- 2,100,000
- 2,200,000
- 2,300,000
- 2,400,000
- 2,500,000

Number of Documents Viewed:
- 0
- 50,000
- 100,000
- 150,000
- 200,000
- 250,000
- 300,000
- 350,000
- 400,000
- 450,000

Time Period:
- Nov-00
- Feb-01
- May-01
- Aug-01
- Nov-01
- Feb-02
- May-02
- Aug-02
- Nov-02
- Feb-03
- May-03
- Aug-03
- Nov-03
- Feb-04
- May-04
- Aug-04
- Nov-04
- Feb-05
- May-05
- Aug-05
- Nov-05
- Feb-06
- May-06
- Aug-06
Infobuttons: Standardization

• **What to Standardize**
  – API calls by CIS to IM and by IM to knowledge sources
  – API call by IM to knowledge sources
  – **Value:** Organizations + vendors need to support only one kind of interface

• **HL7: Current status**
  – Balloting process
    • Main standard = XML, RIM-based call still in progress
    • Ancillary = HTTP/URL-based implementation guide: Initial approval as DSTU 2007
  – Products developed by vendors

http://www.hl7.org
Infobutton Parameters

- **Parameters**
  - Patient context: age, sex, associated condition (coded)
  - User context: user role (coded)
  - Care setting context (coded)
  - Main search concept (coded)
  - Other: Language, modifier of main search concept (coded) [e.g., treatment, differential diagnosis, etc]

- **Coded attributes**
  - Code, code system, code system name, version, display name
Infobuttons: Recommended Terminologies

- **Problems**: MeSH, ICD9, ICD10, DRG, SNOMED CT
- **Medications**: NDC, RxNorm
- **Lab tests**: LOINC
Infobutton Example

- **Goal**: Provide information regarding the treatment of bacterial pneumonia in a 67-year-old patient

- **Query**

  http://www.eresourcewebsite.com/search.cgi?
  mainSearchConcept=482.9^I9^ICD9^Pneumonia, Bacterial
  &applicationContext=
  ProblemList^HL7IBAppContext^2.5^ProblemList
  &patientAge=67
  &patientGender=M^HL70001^Administrative sex^2.5^Male
  &language=eng^ISO639.2^Languages^2.5^English
  &modifier=^^^treatment
Standardization: Next Steps

- Promulgate (HL7) standard -> (vendor) implementations

- **Problem:** No standard way to communicate between EHRs and knowledge sources
  - Mark up resources
  - Possible standard formalism for clinical practice guidelines

- **Status (3/2008):** Initial proposal for HL7 standard still being balloted
  - URL-based standard (“implementation guide”) nearly approved
  - v3/XML-based standard still needs work
Infobuttons: Do They Work?

- **Study: Medication infobuttons**
  - N = 18 clinics, 359 users, 4961 patients
  - Avg use = 2/month (21 sec/session), 1.2% of encounters
- **Survey:**
  - Answered questions 84% of time
  - 15% resulted in change of care

Infobuttons: Assessment

- **Limitation:** Partly “pull” technology
  - Prompted by presence of something in EHR
    - Medication, problem, etc must be entered first
  - Relies on user to initiate
  - Some allow asking of free-form questions not linked to current EHR content

- **Benefits**
  - Context-specific
  - Links to multiple knowledge sources
  - Sometimes integration of different sources
Arden Syntax


- Formalism for procedural medical knowledge

- Unit of representation = Medical Logic Module (MLM)
  - Enough logic + data to make a single decision
  - Generate alerts/reminders

- Adopted by several major vendors

Guideline Model: GLIF

- **Guideline Interchange Format**

- **Origin:** Study collaboration in medical informatics

- **Now:** GLIF3
  - Very limited implementation

- **Guideline** = Flowchart of temporally ordered steps
  - Decision & action steps
  - Concurrency: Branch & synchronization steps

GLIF (continued): Levels of Abstraction

- **Conceptual**: Flowchart

- **Computable**: Patient data, algorithm flow, clinical actions specified

- **Implementable**: Executable instructions with mappings to local data
Guideline Model: GEM

• Guideline Elements Model = Current ASTM standard

• Mark up of a narrative guideline into structured format using XML
  – Not procedural programming
  – Tool = GEM Cutter

• Resulting structure might be used to translate to executable version

• **Model** = 100+ discrete elements in 9 major branches
  – identity and developer, purpose, intended audience, development method, target population, testing, revision plan and knowledge components

• **Iterative refinement**: Adds elements not present verbatim but needed for execution

• **Customization**: Adding meta-knowledge
  – controlled vocabulary terms, input controls, prompts for data capture
GELLO = Common Expression Language

- **Purpose**: Share queries and logical expressions
  - Query data (READ)
  - Logically manipulate data (IF-THEN, etc)

- **Initial rationale**: Stepping stone to a RIM-compliant guideline formalism
  - Based on OMG OCL

- **Initial version**: ANSI standard release 1 = May, 2005

GELLO: Examples

- **Queries**
  
  Observation.select(coded_concept='03245')

  Observation.selectSorted(coded_concept="C0428279")

- **Expressions**
  
  - The variables calcium and phosphate are not null
    
    calcium.notEmpty() and phosphate.notEmpty()

  - The patient has renal failure and the product of calcium and phosphate exceeds a threshold signifying osteodystrophy

    renal_failure and calcium_phosphate_product > threshold_for_osteodystrophy
GELLO: Status

• 2006
  – Tool release by Medical Objects (Australia)
  – Demonstration project: e-Prescribing prior authorization rules
GELLO: Status

• 2007 - 8
  – Authoring tool release by InferMed (UK). Preview at Atlanta meeting 9/2007
  – Demonstration projects
    • Possible: Clinical trial
    • Australia (Medical Objects + Haematology Society + Leukaemia Society of Australia): Guideline representation in a GLIF context
  – Result of demonstration projects
    • BNF revision
    • Work on vMR as a RIM-derived data model for decision support
Decision Support Services (DSS) Standard

- Approved as HL7 DSTU 2007
- Standard for representing communication between an EHR and a “black-box” CDSS
- Consistent with an overall SOA
- Status: Vendor implementations + collect experience to refine DSTU to create full standard
Guideline Formalism Challenges

• **Goals:** Shareable/reusable logical units to avoid re-inventing the wheel when implementing guidelines

• **Mapping local data models and terminologies**
  – Need to be able to retrieve data
  – No widely agreed standard

• **Formalism itself**
  – Multiple models: Arden, GEM, GELLO, GLIF, ProFORMA, EON (ontology-based), etc
Representation of Quality Indicators

- **Subset of guideline challenge**: Measures + decision support across a population
- **Infrastructure**: Data + Knowledge representation
  - Data: QRDA = Specification of HL7 CDA to represent data needed by quality measures
  - KR: Many possibilities, active work
- **Example**: Arden Syntax and ACOVE
  - N = 39 measures applicable to EHR/administrative data
  - Arden can represent logic of all
  - 38% limited by lack of data in a typical EHR
vMR: Virtual Medical Record

• **Definition**: Data model, based on the HL7 v3 RIM format, for representing clinical information *inputs* and *outputs* to/from clinical decision support services

• **Functionality**: Clinical information systems use a standard model to represent data communicated with a clinical decision support system

• **Current use case**: Breast cancer screening and counselling
Continuity of Care Document (CCD)

• **CCD** =
  – Clinical Document Architecture (HL7 CDA) +
  – Continuity of Care Record (ASTM CCR)

• **CCD**: XML-based representation of the clinical record using a standard data model
  – Paper or digital exchange

• **Proposed standard**: Implementation guide to use CCD for plan-to-plan PHR exchange
  – Now being balloted in HL7
Too Many Standards: Harmonization

• **Back End** = HITSP
  – Picking or aggregating a winner among extant standards
  – **Current CDS work**: Facilitate KR formalism for quality indicators
    • Partner with AMA/NCQA initiative
    • Partner with NQF: Endorsement of QIs

• **Front End** = Joint development among SDOs
  – **JIC** = HL7 + CEN/TC 251 + ISO/TC 251
  – **CCD**: CCR (ASTM) + CDA (HL7)
  – HL7 + CDISC
Conclusions

- PHRs = Useful part of an overall EHR
  - Need for CDS + need for data to drive CDSS
  - Positive consumer attitudes

- Standards = important to realize the (CDS) benefits of PHRs
  - Infobuttons
  - Guideline formalism

- More work is needed, including harmonization
Thank you!

- Lola Ogunyemi
- NLM / AHRQ

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