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# Interoperable Personal Health Records in Care Transitions



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## Objectives

- Explore key informatics issues of PHRs through “medications in care transitions” use case
  - Types of PHRs
  - PHR platforms
  - Regional Health Information Organizations
  - User-centered design
  - The role of standards



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## Personal Health Records in General

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# What Is a Personal Health Record?

- Conceivably paper, but generally electronic in informatics context
- Markle Foundation Connecting for Health Report
  - *An electronic application through which individuals can access, manage, and share their health information, in a private, secure, and confidential environment.*
- Three basic types
  - Standalone
  - Tethered ("patient portal")
  - Interoperable




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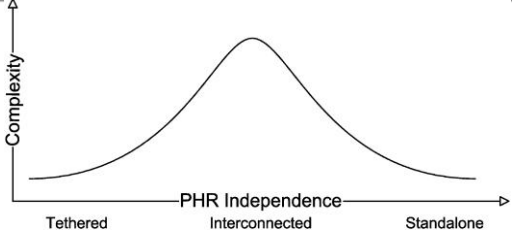
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# The Spectrum of PHRs




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# Why Personal Health Records?

- Improve portability of health information
  - In personal emergency
  - In disaster (e.g. Katrina)
  - In our fragmented health care system:
    - "Get rid of the clipboard"
- Empower patients
  - Better adherence to (e.g. to medication regimens)
  - Patient as driver of quality of care provided (preventive care, chronic disease management)
  - Improve self-care




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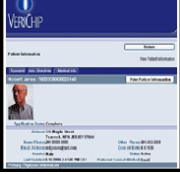
## More Daring Portable Storage



Step 2. Medical provider reads unique ID from Verichip



Step 3. ID number is used to reference patient's secure records



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## Problems with Standalone

- You have to enter all the information
- Your doctors may not use it after all
  - Can't read it
  - Doesn't trust it
  - Doesn't want to be bothered



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## Tethered PHR

- Also known as "patient portal"
- Most common form of PHR
- Often Offered by larger institutions
  - e.g. VA (My Health eVet), Kaiser
  - May be bundled with EMR (e.g. Epic MyChart)
- May include
  - Secure electronic messaging
  - Administrative functions (scheduling, refills)
  - Clinical information (meds, test results)
  - Consumer health information
  - Chronic disease management tools



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# University of Colorado Hospital Patient Portal



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# Tethered PHR Characteristics

- Advantages
  - Autopopulated
    - (don't have to enter data yourself)
  - Suite of useful tools
  - Has a business model!
- Disadvantages
  - Not comprehensive
  - You can't control release (can't take it with you)
  - You can't control content



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# Interoperable PHR

- The holy grail
  - Comprehensive
  - Portable
  - Owned by the patient
  - Controlled by the patient
  - Able to interact with "widgets"



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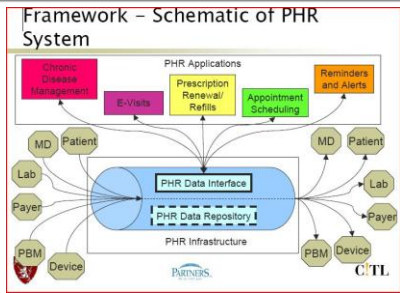
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# Interconnected PHR: General Schema



From Middleton B: The Value of PHR in the Clinical Setting




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# Interconnected PHR: Microsoft HealthVault Schema




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# Major PHR Platforms



- Microsoft HealthVault
  - Major focus on device connectivity – capitalize on support of devices in Windows
  - Relies on vendor UIs
  - Business model: ad revenue when search used



- Google Health
  - Less device connectivity, more emphasis on developing relationships with info suppliers
  - Offers its own UI
  - Business model also based on searches



- Dossia
  - Based on nonproprietary "Indivo" platform
  - Sponsored by employers (e.g. Wal-Mart)




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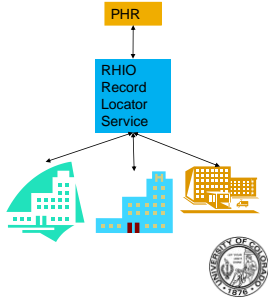
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## Involvement of Regional Health Information Organizations (RHIOs)?

- Probably not
- Data sharing agreements are very sensitive
- Health care organization is better authenticator of PHR user than RHIO
- No business model for RHIO (no membership or transaction fees)




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## Interoperable PHR: Challenges

- Security / protecting privacy
  - Maintaining patient control
  - But ensuring some release
  - And providing emergency access
- Exchanging information
  - Transmission standards: HL7
  - Content standards:
    - Could save as PDF images
    - Better to use ASTM Continuity of Care Record (CCR)




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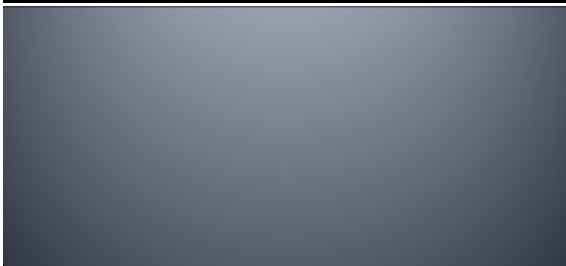
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## A Deeper Dive into Standards




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## Messaging: HL7 2.x EDI-Based (commonly used)

```
MSH|^~\&|DDTEK LAB|ELAB-1|DDTEK OE|BLD014|200802160930||ORU^R01^ORU_R01|CTRL-9876|P|2.4|
PID||010-11-1111||Estherhaus^Eva^E^^^^I|Smith|19720520|F|||266 Sherwood Forest Dr.^Baton
Rouge^LA^70809|||(225)334-5232|||(225)762-1213|||AC01011111||76-B4335^LA-20070520
OBR|1|948642^DDTEK OE|917363^DDTEK LAB|1564-5^GLUCOSE|||200802160730|||020-22-2222^
Levin^Egates|Anna^~^MD^Micro-Managed Health Associates|||||F|||||030-93-3333^
HoneywellCarsonc&MDC
OBX|1|SN|1564-5^GLUCOSE^~^POST 12H CFST:MCNC:PT:SER/PLAS:QN||~175|mg/dl|70_106|H||F
```



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## Messaging: HL7 3.x XML Based (uncommonly used)

```
<?xml version="1.0" encoding="UTF-8"?>
<message xmlns="urn:h7-org:v3" xmlns:dts="urn:h7-org:v3" xmlns:si="http://www.w3.org/2001/XMLSchema-instance">
  <id root="2.24.750.2.937172.4433" extension="CTRL.9876"/>
  <creation_time value="2005-02-15T09:30:00-05:00"/>
  <version_id value="3.0"/>
  <interaction_id root="2.24.750.2.937172" extension="POLB_IN0044107">
    <processing_id code="P"/>
    <report_ack_id code="RST"/>
    <interactionTarget xsi:type="POLB_MT004101">
      <ObservationEvent>
        <id root="2.24.750.2.937172.4433" extension="917363" assigningAuthorityName="DDTEK LAB7"/>
        <cd code="1524-S" codeSystemName="LN" displayName="GLUCOSE POST 12H CFST:MCNC:PT:SER/PLAS:QN"/>
        <status_id code="Completed"/>
        <effective_time>
          <center value="2005-02-15T07:30:00-05:00"/>
        </effective_time>
        <activity_time>
          <center value=""/>
        </activity_time>
        <priority_id code="A"/>
        <value xsi:type="dt:PQ" value="175" unit="mg/dl"/>
      </ObservationEvent>
    </interactionTarget>
  </interaction_id>
</message>
```



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## Content: ASTM Continuity of Care Record (CCR) Standard

- From Liora Alschuler, 2006 LTC Summit
- Shows XML encoding of CCR
  - Readable with style sheet
  - Potentially computable



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# Care Transitions: Challenges

- Care transition: Moving from one setting of care to another (esp. hospital → home)
- Abrupt: information overload
- Risk of readmission or worse
  - Wrong meds taken
  - Wrong care of wounds, catheters, intravenous lines
  - Not sure what to look out for
  - Not sure who to follow up with and when




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# Care Transitions Intervention

Care transition coach and paper PHR to address "four pillars"

1. Medication list
2. Follow up plans
3. Self-care
4. Red flags




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# Paper PHR in Care Transitions Intervention

**Personal Health Record**

The Personal Health Record of \_\_\_\_\_

**Personal Information:**  
 Address \_\_\_\_\_  
 Home Phone # \_\_\_\_\_  
 Work Phone # \_\_\_\_\_  
 Cell Phone # \_\_\_\_\_  
 PCP Name \_\_\_\_\_  
 Advance Care?

**Identification Information:**  
 Address \_\_\_\_\_  
 Home Phone # \_\_\_\_\_  
 Patient ID Number \_\_\_\_\_

**Emergency Information:**  
 Name \_\_\_\_\_  
 Address \_\_\_\_\_  
 Phone # \_\_\_\_\_  
 Relation to Patient \_\_\_\_\_

**REMEMBER**  
 to take this Record with you to all your doctor visits

**Medical History**

- Asthma
- Abnormal Heart Rhythm
- Cancer
- Diabetes
- Hardening of the Arteries
- Heart Disease
- Heart Failure
- High Blood Pressure
- Hip Fracture
- Lung Disease
- Medication/Surgical Risk conditions
- Osteoporosis
- Stroke
- Other Diagnoses \_\_\_\_\_

To better manage my health and medications, I will:

- Ask my healthcare provider with the pharmacist or visiting nurse if I should use a medication dispenser.
- Get the answers to my questions.
- Call my doctor if I need to change how I take my medications.
- Tell my doctor when I'm taking my medications, including over-the-counter drugs, herbs, and supplements.
- Update my Medication Record when any changes to the medications.
- Ask my doctor, nurse, and pharmacist to help me understand how to take my medications.
- Ask my pharmacist, nurse, and pharmacist to help me understand how to take my medications.
- Ask my pharmacist, nurse, and pharmacist to help me understand how to take my medications.

**Medication Record (Sample)**

Name	Dose	Frequency	Notes?
Aspirin 81	1 tablet 2 times a day	Everyday	N
Colchicine 1.2	2 tabs per week	Every 7 days	N
Warfarin	5 mg once per day	Every day	N
Metoprolol	25 mg twice per day	Twice a day	N
Metformin	500 mg twice	Twice a day	N
Multivitamin	once per day	Once a day	N

**Alerts:** Percidin + Rash

**Notes for My Primary Care Physician:**

1. Do I need to take the Transtexa even when I do not have swelling?
2. How long will it take to resolve my health issue?
3. When is my next blood draw to check the Warfarin?

**Intervention Activities Checklist**

Before I leave the Care Facility, the following tasks should be completed:

- I have been involved in decisions about what I will do when I leave the hospital.
- I understand what symptoms I need to watch for and when to call my doctor.
- I understand how to take my medications and when to call my doctor.
- I have the name and phone number of a person I can call if I have a question about my medications.
- I understand what my medications are for and how to take them, and how to take them.
- I understand the potential side effects of my medications and when to call my doctor.
- I understand what symptoms I need to watch for and when to call my doctor.
- I understand how to take my medications and when to call my doctor.
- I understand what my medications are for and how to take them, and how to take them.




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## Care Transitions Intervention: Persistent Challenges

- Many patients identify medications by shape, size, and color, not name
- Drug names are redundant and inscrutable: easy to unintentionally duplicate medications
  - "Tiazac" and "Cardizem" are the same ingredient
  - "Norvasc" and "Plendil" are slightly different ingredients in the same class
- Authoritative drug information isn't accessible
  - For individual medications
  - For drug regimen
- "Intended" medication list isn't always clear




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## Project HealthDesign: Activating the Medication List

- Provide pictures
- Prevent duplication of medications
- Make it easy to get authoritative information
- Help patients build and "reconcile" medication lists by linking to sources of personal medication information




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## Presenting Pictures

- User studies: confirmed that patients highly value pictures of medications
- To know what picture to show, must know what has been dispensed → must have NDC code
  - Using a Micromedex database indexed by NDC code
  - Making sure not to be thrown off by arbitrary NDC codes!
  - NLM is working on non-proprietary image set




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## Prevent Duplication of Medications

- Pharmacist experts confirmed that this is a common problem
- Can identify duplicate ingredients if you normalize to a common generic name or code
- Identifying duplicate classes (such as "calcium channel blockers") requires proprietary medication knowledge applications, e.g.
  - ThomsonReuters Micromedex
  - Wolters Kluwer Medi-Span
  - First Data Bank




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## User Studies: Unmet Needs for Authoritative Information

- Patients have a lot of concerns, especially related to possibility that medications could cause loss of autonomy
- Common concerns:
  - Will this medication cause a side effect?
  - I'm not feeling well—could it be one of my medications?
  - Will it hurt my body to take so many medications?
  - Are the medications safe to take together?
- Information sources
  - Internet: Lots of information, but not authoritative
  - Doctor: Little opportunity in busy visit: "don't want to bother the doctor"
  - Pharmacist: Highly valued, but only interact when getting meds




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## Provide Authoritative Information

- Information on individual medications
  - Proprietary as above
  - Non-proprietary from NLM
    - DailyMed
    - MedlinePlus
- Information on medication regimens
  - Proprietary applications as above
  - Google Health uses Safe-Med
  - Facilitate pharmacist consultation?




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# Building and Reconciling the Medication List

- Seems easy—but it is a great challenge!
- No authoritative medication list in cyberspace
- Export of medication lists isn't common
  - Dispensed/Fulfilled information
    - SureScripts/RxHub: Only to physicians who e-prescribe
    - Some pharmacy systems linking to GoogleHealth and HealthVault
  - Prescribed Information
    - Many doctors don't use EMRs
    - Even when EMRs used, med lists aren't commonly exported
    - Especially hospital discharge med list
- Too hard for patients?




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# Building and Reconciling the Medication List



- Putting two lists side by side was very confusing
- Novices didn't like drag and drop metaphor
- Patients were intimidated by "computer list"
- Simplified interface to reduce anxiety




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# Project HealthDesign Future Directions

- Link to real sources of medication information
- Incorporate medication scheduling assistant
  - Assistance in scheduling complicated regimens
  - Prompts and reminders
  - Assessment of adherence




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