Personal Health Records

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Biomedical Informatics Course
Marine Biological Laboratory in Woods Hole, MA
- June, 2010 -
Objectives

• Outline the motivation for Personal Health Records (PHRs)
• Describe the different models for PHRs
• Describe the main components of PHRs
• Explain interoperability requirements for PHRs
• Illustrate benefits of PHRs through utilization scenarios
• Outline existing incentives that promote PHR adoption
• Outline privacy issues related to PHRs
• Summarize available PHR products and their business models
• Outline challenges and opportunities related to PHRs
Expected Results

• As a result of participating in this activity, learners will be able to:
  – Explain uses and benefits of Personal Health Records (PHRs)
  – Describe the main components of a PHR
  – Describe the different models for PHRs
  – Explain existing incentives to adopt PHRs
  – Outline important challenges and opportunities related to PHRs
1. **Background**
   - Motivation for Personal Health Records (PHRs)
   - Main implementation models for PHRs
   - Incentives promoting PHR adoption

2. **PHRs from a consumer perspective**
   - Uses and benefits of PHRs
   - Typical and advanced features
   - Privacy issues related to PHRs

3. **PHRs from an informatics perspective**
   - Components of a PHR system
   - Interoperability requirements for PHRs
   - Examples of PHR design concepts

4. **Challenges and opportunities**
(1) Background

Motivation for PHRs
Main types
Incentives to use a PHR
• PHR: **personal** (patient) **health record**
• PCHR: **patient-controlled** health record
• PHR-S: patient health record **system**
• PHA: personal health **applications**
• PEHR: personal electronic health record
• **Patient Portal**: view to a provider’s EHR
• **Health Record Bank**: persistent secure health information repository (multiple sources)

• **E-visit**: secure messaging between patients and providers; evaluation & recommendations
Definition (1)

• ”... is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it.” (Markle Foundation, 2003)

• “... is a repository of information considered by that individual to be relevant to his or her health, wellness, development and welfare, and for which that individual has primary control over the record’s content.” (ISO, 2009)
• “... an electronic, universally available, *lifelong resource* of health information needed by individuals to make health decisions. Individuals *own* and *manage* the information in the PHR, which comes from healthcare *providers* and the *individual*. The PHR is maintained in a *secure* and *private* environment, with the individual determining *rights of access*. The PHR is separate from and does *not replace* the legal record of any provider.”
Motivation: consumer needs

- **Control** over personal health ("patient-consumer")
  - Active participation (co-responsibility), empowerment
  - Improved quality and safety

- **Communication** with providers (increased frequency)
  - Appointments, medication refills, questions
  - Electronic visits (*e-Visits*)
  - Health record summary

- **Opportunity to learn** about diseases and treatments
  - Access to test results, reference resources, FAQs
  - Facilitate understanding and action (health literacy)
Motivation: provider needs

- Simplified **data gathering** from patients
  - Glucose levels, diet, exercise, pain, etc.
  - Forms and surveys
  - Home monitoring
- **Communication** with patients (decrease overhead)
  - Appointments, medication refills, questions
  - Electronic visits (**e-Visits**)
Motivation: financial

- Decrease healthcare costs for payers and employers
  - Disease management and wellness programs
  - Treatment compliance
- New sources of revenue (commercial interests)
  - Attract new users with healthcare interests
  - Targeted advertisement
  - Personalized decision support
  - Platform licensing (hosting)
  - Data licensing
    - Source of revenue for consumers
Why use a PHR?

• **Knowledgably** discuss your health with healthcare providers
• Provide **information** to new caregivers
• Have easy **access** to your health information while traveling
• Access your information when your doctor’s office is closed
• Record your **progress** toward specific health-related goals
• **Refer** to physician instructions, prescriptions, allergies, medications, insurance claims, and more
• **Track** appointments, vaccinations, and numerous other wellness healthcare services

Why should you keep a PHR? [www.myphr.com](http://www.myphr.com) (AHIMA)
# Health records

## EHR

- **Provider** is primary user and custodian
- Scope defined by provider *(narrow)*
- Access control managed by provider *(intra)*
- Interoperability is **useful**

## PHR

- **Consumer** (patient) is primary user and custodian
- Scope defined by consumer *(broad)*
- Access control managed by consumer *(inter)*
- Interoperability is **critical**
# Data types and sources

**Table 1**  
Sample PHR Data Types and Potential Sources

<table>
<thead>
<tr>
<th>Data Type</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem list</td>
<td>Patient, EHR</td>
</tr>
<tr>
<td>Procedures</td>
<td>Patient, EHR, or claims</td>
</tr>
<tr>
<td>Major illnesses</td>
<td>Patient, EHR, or claims</td>
</tr>
<tr>
<td>Provider list, potentially linked to problems</td>
<td>Patient, EHR</td>
</tr>
<tr>
<td>Allergy data</td>
<td>Patient, EHR</td>
</tr>
<tr>
<td>Home-monitored data (eg., BP, glucose, peak flow)</td>
<td>Patient, automated interface with equipment</td>
</tr>
<tr>
<td>Family history</td>
<td>Patient, EHR</td>
</tr>
<tr>
<td>Social history and lifestyle</td>
<td>Patient, EHR</td>
</tr>
<tr>
<td>Immunizations</td>
<td>Patient, EHR, immunization registries</td>
</tr>
<tr>
<td>Medications</td>
<td>Patient, EHR, claims history (partial data)</td>
</tr>
<tr>
<td>Laboratory tests</td>
<td>Patient, EHR, commercial laboratories</td>
</tr>
</tbody>
</table>

PHR = personal health record; EHR = electronic health record.

Models of PHRs

Figure 1. Range of complexity in various approaches to personal health records (PHRs).

Models of PHRs: reliability vs. control

Figure 1. Range of complexity in various approaches to personal health records (PHRs).

Debate about models

• “One is a **stand-alone** ... Our bet, however, is that the other option, the "**integrated PHR**" that is an extension of physicians' electronic health records (EHRs), will go **further** in facilitating the type of **physician–patient relationship** that will **improve** health and health care, at a lower **cost**.”

Best of both models?

Google Health

Google Health is an online health information management service that is available, free of charge, through Google, the largest Internet search company in the world. Like MyChart, Google Health securely stores your personal health-related information and is accessible through any computer with an Internet connection. Unlike MyChart, Google Health allows you to add information about yourself. Because MyChart and Google Health are compatible services, MyChart users can choose to:

- Create their own, personal Google Health account (much like your MyChart account, including a secure log-in name and password that can only be accessed by you).
- Select information from your MyChart account and copy it into your secure Google Health account. You can even choose to have your MyChart and Google Health accounts updated automatically so that any information entered into one will be immediately copied into the other.
- Enter information into your Google Health account about health-related activities or services you do not receive from Cleveland Clinic (such as from your family dentist or any other physician you choose to visit).
- Test a number of Google Health’s features and options to determine how easy they are to use, how useful they would be, and how Google might improve the service over time.

If you would like to begin using this new online health information management service, please click “Manage My Health” menu selection in MyChart and follow the instructions to access this new feature.

Cleveland Clinic's MyChart & Google Health - see [http://my.clevelandclinic.org/eclevelandclinic/mychart/features.aspx](http://my.clevelandclinic.org/eclevelandclinic/mychart/features.aspx)
Incentives to adopt PHRs

+ American Recovery and Reinvestment Act (ARRA)
  • $19 billion for advancing HIT; incentives for physicians and hospitals to adopt EHRs
  • 100% EHR adoption by 2014
  • IFR: “Provide patients with an electronic copy of their health information” (Human readable + Electronic: CCD Level 2 or CCR)

+ Insurers start to reimburse for e-visits ($25-$35)
+ CMS proposed rule to reimburse for telehealth
+ Promotion of the Medical Home model (PCPs)
+ CMS pilots encouraging Medicare beneficiaries
  • MYPHRSC (SC) and Medicare PHR Choice (AZ and UT)
    – Portability enables patients to change providers
    – Clear applicability limited to chronic illness
With a PHR, you may be able to get to your information anywhere and anytime you have access to the Internet. Some PHRs simply provide a way for you to enter your own information. Other PHRs provide more services, such as making it possible for your pharmacy or doctor’s office to add information electronically. Some PHRs may charge a fee for their services. Talk to your doctor or someone from your health plan to learn more about your PHR options.

You may have health information in lots of places—at home or in a doctor or hospital records. Personal health records (PHRs) are confidential, easy-to-use electronic tools that can help you manage your health information. PHRs may be an easier way for you to keep all your health information—like doctor or hospital visits, allergies, shots, or a list of your medicines—in one place.

Having a PHR can help you provide more complete information to your health care providers or family members. With all your health information in one place, you may be able to avoid unnecessary procedures or tests and to provide critical information about your health in a medical emergency. A PHR may help you save time and money, and improve the quality of care you get.

PHRs may have other great features to help you manage your health information.

- Allergies to food
- Health conditions
- Over-the-counter or herbal medications you are taking
- A list of your doctors
- Emergency contacts

In addition to keeping all your information in one place, some PHRs may make it easier for you to do the following:

- Order prescription refills online
- Schedule appointments with doctors
- Get helpful information on things that matter to you, like diabetes or high blood pressure

With a PHR, you control your information. Since you are the only one who has access to your information, you are in control of who sees it. Most companies that provide PHRs offer a secure site to protect and keep your information safe.

Health plans and most health care providers who offer PHRs must give you a Notice of Privacy Practices, which tells you how they keep your personal information private and safe. If you don’t get a privacy notice, ask the health plan or provider for a copy, or check your PHR’s website.

Here are some questions to ask when choosing a PHR:

- Is there a monthly or annual fee to use the PHR?
- What kind of information can I store in the PHR?
- What are the PHRs’ privacy and security policies?
- Can I give access to my doctors or family members?
- Can I refill prescriptions or make appointments through the PHR?
- Can the PHR generate reports of my health information?
- Does the PHR offer educational health information?

To Learn More

- Visit www.medicare.gov/phr
- Talk to your doctor or health plan and see if they can help you find or use a PHR.
Summary of Vendors Participating in Medicare PHR Choice

This chart shows you basic information about the Personal Health Record vendors and their products offered as part of Medicare PHR Choice. Because the PHRs vary, Medicare recommends you visit each of the vendor websites to see their tool and features before you make your choice. The beginning of this summary compares various features followed by additional features of each PHR tool. For more information on Medicare PHR Choice and to sign-up, visit http://www.medicare.gov/phr/ on the web.

<table>
<thead>
<tr>
<th>PHR Vendor</th>
<th>Google</th>
<th>Health Trio</th>
<th>NoMoreClipboard.com</th>
<th>Passport MD</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHR(s) Offered</td>
<td>Google Health</td>
<td>Basic</td>
<td>Basic</td>
<td>Premium</td>
</tr>
<tr>
<td>Cost</td>
<td>Free</td>
<td>Free</td>
<td>Free</td>
<td>$9.95/year</td>
</tr>
<tr>
<td>Displays text in claims in understandable language</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Can enter your own health information</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Ability to authorize family or providers to view record</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Has links to health education information</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Has print capability</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Can import pharmacy data</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Can import laboratory data</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Can view radiology images</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Can communicate with providers (e.g. email)</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Has graphic displays of clinical information</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Can communicate with medical devices</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Has authorizations and consent for treatment forms</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Has personal support available to help populate PHR</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Can view tool in other languages</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

Updated February 16, 2010
Welcome to My Personal Health Record, South Carolina (MyPHRSC)!
MyPHRSC is a free and secure electronic Personal Health Record that stores your Medicare claims history for the past 24 months in one convenient place. Updated daily, the health record provides you with one place where you can track your medical history. With MyPHRSC, you don’t have to search through your paper records to find what you need. You can access your records in one place, wherever you are, and whenever you need them. You will have access to your Medicare information 48 hours after you register. With MyPHRSC, you can view and manage the following Medicare claims information:

- Provider Visits
- Hospitalizations
- Medical conditions

You can also add additional health related information about yourself to your record. It's Your Health. Your Record. Online, Anytime!

Register | Forgot My Password | Customer Service | Demo | FAQs
MyPHRSC preliminary evaluation

Approach: Discussion groups and user observation studies with beneficiaries and providers; 12 months of utilization data

“... More than half of all registrants only logged in to MyPHRSC during one calendar month of the pilot.”

2,189 out of 3,059 ever logged in = 71.5%; 4,114 registered
Value of PHRs

- Report from the Center for Information Technology Leadership (CITL) examining direct financial costs and benefits
  - PHRs offering 8 core functions:
    - Complete medication list
    - Complete test results
    - Remote monitoring
    - Self-management
    - Appointment scheduling
    - Medication renewals
    - Pre-encounter questionnaires
    - E-visits

Value of PHRs - overview

- Interoperable PHRs to 80% population in the US provide a net value of $19 billion annually
  - $3.7 billion acquire; $1.9 billion annually maintain; 10-year rollout
- Break-even point for a single PHR installation:
  - 52,000 users for interoperable PHRs
  - 59,000 users for provider-tethered PHRs *(lack of economies of scale)*
  - 62,000 users for payer-tethered PHRs
  - 47 million users for third-party PHRs
- Net value is highly dependent on the reimbursement model of an e-visit *(estimated from $0 to $25)*
- Development and adoption of interoperability standards
- Business models that **align** those paying for the PHRs and those receiving the benefits

Value of PHRs by model

National Annual Net Value by PHR Architecture

(2) Consumer perspective

Uses and benefits of PHRs
Typical and advanced features
Privacy issues related to PHRs
Expected benefits for consumers

- Support wellness activities
- Improve **understanding** of health issues
  - Support understanding and appropriate use of medications
- Increase sense of control over health
  - Support healthcare decisions and responsibility for care
- Increase **control over access** to personal health information
- Support timely, appropriate preventive services
- Strengthen communication with providers
  - Reduce hassle through online appointment scheduling and refills
- Verify **accuracy** of information in provider records
- Support **home monitoring** for chronic diseases
- Support **continuity of care** across time and providers
- Manage insurance benefits and claims
- Avoid duplicate tests
- Reduce **adverse drug interactions** and **allergic reactions**
- Increase access to providers via **e-visits**

**Personal Health Records and Personal Health Record Systems. A Report and Recommendations from the National Committee on Vital and Health Statistics, February 2006.**
Expected benefits for providers

- Improve access to (more) data from other providers and the patients themselves
- Increase knowledge of potential drug interactions and allergies
- Avoid duplicate tests
- Improve medication compliance
- Provide information to patients for both healthcare and patient services purposes ("information prescriptions")
- Provide patients with convenient access to specific information or services (e.g., lab results, Rx refills, e-visits)
- Improve documentation of communication with patients

Expected benefits for payers & employers

**Payers**
- Improve customer service (transactions and information)
- Promote *portability* of patient information across plan
- Support *wellness* and *preventive care*
- Provide information and education to beneficiaries

**Employers**
- Support wellness and preventive care
- Provide convenient service
- Improve *workforce productivity*
- Promote empowered healthcare consumers
- Use aggregate data to *manage* employee health

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Requirements (1)

- Access control
  - Secure password-protected patient access
  - Capacity to provide authorized provider access
  - Capacity to provide directed emergency access

- Information for providers
  - Accurate entry of past and current medical conditions, including information about diagnosis and treatment
  - Accurate entry of past and current medications, including information about indication, dose, frequency, and duration
  - Verification of laboratory test results
  - Verification of diagnostic study results
  - Verification of immunizations, including information about dates and sequences

Requirements (2)

- **Information for patients**
  - Accurate entry of medical conditions and medications
  - Capacity to provide links to consumer health care information
- **Interpretation of information**
  - Accurate entry of medical conditions and medications
  - Verification of laboratory test results and diagnostic study results
  - Capacity to interpret laboratory tests and diagnostic study results
- **Monitoring and disease management**
  - Accurate entry of medical conditions and medications
  - Verification of monitoring study results
  - Capacity to interpret monitoring study results
  - Capacity to provide evaluation and treatment recommendations
  - Capacity to provide secure communication between patients and providers

Primary functions

- Collection
- Sharing (one-way)
- Exchange
- Self-Management

Personal Health functions (1)

- Manage Account holder profile
  - Identify and Maintain a Record
  - Account Holder Demographics
  - Account Holder and Family Preferences
  - Patient Advance Directives
  - Consents and Authorizations
  - Account Status

- Manage Historical Clinical Data and Current State Data
  - Patient Originated Data
  - Data from External Administrative Sources
  - Data and Documentation from External Clinical Sources
  - Ad Hoc Views of the Record
  - Current State Data Set:
    - Problem Lists; Medication Lists; Test Results; Allergy, Intolerance and Adverse Reaction List; Immunization List; Medical History; Surgical History; Family History; Personal Genetic Information; Social History

Personal Health functions (2)

- Manage Wellness, Preventive Medicine and Self Care
  - Personal Clinical Measurements and Observations
    - Personal Observations and Care; Communication with Medical Devices
  - Account Holder Implemented Care Plans
  - Provider Implemented Care Plans
  - Medications
  - Tools and Functions to Assist Self Care
    - Calendar; Tasks; Registry of Actors; Reminders; Alerts; Recommendations
  - Population Health and Wellness
    - Public Health Reporting; Public Health Risk Alerts

- Manage Health Education

- Manage Account Holder Decision Support
  - Guidelines and Protocols
  - Drug Interaction Checking
  - Integration with Third Party Clinical Decision Support Services
  - Configured Alerts

• Manage Encounters with Providers
  – Patient Health Data Derived from Administrative and Financial Sources
  – Self-Assessments (i.e., Symptoms)
  – Communication Between Provider and Patient and/or the Patient Representative
  – Data and Documentation from External Clinical Sources
  – Provider Assessments
  – Referrals and Referral Process
  – Patient Specific Care, Instructions, Treatment Plans, Guidelines and Protocols
Supportive functions

- **Provider Management**
  - Selection of Providers; Account Holder’s Provider Information; Health Care Provider Information; Provider Transparency Information (e.g., quality, performance); Healthcare Facility Information; Healthcare Facility Transparency Information; Surveys on the Healthcare Experience

- **Financial Management**
  - Capture and Read Health Insurance Health Insurance Account and Benefit Information; Health Insurance Plan Benefit Information; Standard Reporting; Ad Hoc Query and Report Generation

- **Administrative Management**
  - Account Holder Demographics; PHR Conditions of Use; Data Masking for Sensitive or Selective Information; Manage PHR Output; PHR Data Import and Export; Secondary Use Requests; Requests for Release of Information; Information View; Legal and other Related Documents (Consents and Authorizations; End-of-Life Documents; Documents for Personal Representation)

- **Other Resource Management**
  - Clinical Research Information (Capture Genomic/Proteomic Data and Documentation from External Clinical Sources, De-Identified Data Request Process, Member Notification of Clinical Trials, and Enrollment in Clinical Trials or Research); Registry Notification and Management; Donor Information; Manage Account Holder Education Material Updates; Account Holder Reminder Information Updates; Public Health Information (Public Health Related Updates, Access to Public Health Information Resources, Health Knowledge Bases, Enrollment in Public Health Programs, Enrollment in Public Health Notices, and Enrollment in Public Health Surveys)

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Infrastructure functions

- **Information Management**
  - Data Management; *Synchronization*; Ad-Hoc Views of the Health Record; Extraction of Health Record Information; Store and Manage **Unstructured** Health Record Information; Store and Manage **Structured** Health Record Information; Patient Locator and Directory Services; Standard Terminologies and Terminology Models; Maintenance and Versioning of Standard Terminologies; **Terminology Mapping**; Administrative Management of Business Rules; **Workflow Management**

- **Interoperability**
  - Interoperability **Standards**; Interoperability Standards Versioning and Maintenance; Standards Based Application Integration; Interoperability Agreements

- **Security**
  - Entity Authentication; Entity **Authorization**; Entity Access Control; **Non-Repudiation**; Secure Data Exchange and Routing; Information **Attestation**; Patient Privacy and Confidentiality; Service Availability; Secure Messaging

- **Auditable Records**

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*Chapter Five: Information Infrastructure Functions*
PHR features

**Five key features and their frequency across 12 PHRs**

1. Secure access to PHR anytime, anywhere, via the Internet, or a portable drive device: 8 implemented, 4 not implemented.
2. Easy input and annotation or updating of comprehensive health related information (e.g., medications, allergies, treatments, etc.): 11 implemented, 1 not implemented.
3. User-friendly structured summary of medical information to healthcare providers: 8 implemented, 4 not implemented.
4. Upload relevant health related documents available in digital format (e.g., scanned images of DNR orders, x-rays, living will, etc.): 8 implemented, 4 not implemented.
5. Access to relevant health-related educational materials available via web links and/or distributed by providers: 5 implemented, 7 not implemented or N/A.

Access Control & Privacy

• Patients should control who sees their data and how their data is used
  – Providers, family, proxies, public health agencies, and researchers (data and cohort recruitment)
  – Software applications (analysis and decision support)
  – Independent access agreements with data consumers

• Lack of federal privacy protection for confidential information managed by entities not covered by HIPAA
  – Stand-alone PHRs, health data banks, etc.

• Proper data de-identification and aggregation

• Engage others with similar conditions (social-networking)

"... give us your data and get something in return."

... we would data-mine your own data in order to help you.

Data privacy

Facebook Unveils Simplified Privacy Settings

"... simple controls to determine whether their information was visible to only friends, friends of friends, or everyone..."

"... Facebook is trying to change privacy on the Internet..."

Palo Alto, Calif. — Ever since Facebook was founded in 2004, Mark Zuckerberg, its chief executive, has pushed its users to share more information about themselves. Time and again, users have pushed back, complaining that some new feature or setting on the site violated their privacy.

But the reaction has rarely been as strong as in the last few weeks, as users, privacy advocates, and governments in many countries lobbied a series of increasingly vociferous complaints against the company. On Wednesday, Zuckerberg responded, unveiling a set of controls that he said would help people better understand what information was sharing online, and with whom.

“It has been a pretty intense few weeks for us,” said Zuckerberg, who added that he had been huddled with other senior executives for the last two weeks to help shape Facebook’s response.

The back and forth between Facebook and its users over privacy is gaining importance as the company’s growth continues unabated. It now has nearly 900 million users around the world, and its policies, more than those of any other company, are helping to define standards for privacy in the Internet age.

The new settings would simplify a system that required users to go into settings and click through confusing options to block information from friends, friends of friends, or everyone on the Internet. Those settings will be applied retroactively to everything users have already published on Facebook. In addition, Facebook said it was changing its directory to show only minimal information.

MIGUEL HELFT and JENNA WORTHAM
(3) Informatics perspective

Components of a PHR system
Interoperability requirements for PHRs
Examples of PHR design concepts
PHR components
Clinical data sources

EHR - Specialist
EHR - OB/GYN
EHR - PCP
EHR - Hospital

High fragmentation and limited interoperability
Data sharing is critical

PHR is a new data source with a ‘different’ vocabulary
Platform model

Figure 1. The Platform Model of Personally Controlled Health Records (PCHR).

Figure 1. The Platform Model of Personally Controlled Health Records (PCHR).

Platform details

- **Project HealthDesign** (Pioneer Portfolio, RWJF)

- **Indivo** (Informatics Program, Children's Hospital Boston)
  - Architecture Overview
**Parent-controlled Pediatric Medical Home Record**

"those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”

• About **12.8%** of children in the US
  – Approximately 9.3 million individuals
  – 20% of households with children include at least one with a special health care need

• Relatively common disorders, such as asthma, attention deficit hyperactivity disorder, and seizures
  – Definition subsumes **100+** congenital and acquired conditions, most of which are very uncommon

CSHCN: Vulnerability

- Considered a particularly vulnerable population that is directly affected by access, cost, quality, and coverage weaknesses in the health care system\(^1\)
- CSHCN consume 80-90\% of health care dollars spend on children\(^2\)

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CSHCN: Care delivery

- Typically,
  - Numerous providers
    - physicians, therapists, dentists, counselors, etc.
  - Different institutions
    - clinics, outpatient centers, hospitals, etc.
  - Multiple environments
    - home, day care, school, etc.
  - Frequent and complex care transitions
- It is rare that these providers and settings exchange information in ways that result in comprehensive, coordinated care
The value of comprehensive and coordinated medical care for children with chronic conditions and disabilities has been demonstrated by several studies:

- American Academy of Pediatrics and the federal Maternal and Child Health Bureau have been promoting the “Medical Home” concept.
Medical Home: Definition

Care provided in the Medical Home is “accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-competent”

– The primary care provider (“Medical Home”) is envisioned as the “central repository” for collecting, managing, and appropriately sharing information

Medical Home: Practice

• A typical pediatric practice will have 200-300 CSHCN
  – Only one or two patients each with any of the less common diagnoses

• Common challenges
  – Maintain knowledge of the many chronic and complex conditions
  – Familiarity with relevant subspecialty and community services and other key resources
Medical Home: Parents

• Desire knowledge about their children’s conditions and about available resources
  – Priorities for information and resources differ from what physicians believe them to be, making it harder to develop effective partnerships

• Families are often highly motivated and find valuable information of which their physicians may be unaware

PedMHR: Motivation

• Parents spend significant time caring for their child, but also:
  – Managing multiple health care providers and the information generated by them
  – Coordinating providers, insurance companies, day care, schools, etc.

• Amount and complexity of information that parents need to understand, remember, and communicate is daunting

• Pediatric Medical Home Record: PedMHR
PedMHR: Needs of parents (1)

• Accurate and complete records of care
  – Enable proper coordination of various providers and caregivers
  – Minimize the duplication of diagnostic and therapeutic interventions
  – Ensure the quality and safety of the health care their child receives

• Prompt access to records (and associated instructions)
  – Facilitate understanding and compliance
  – Enable efficient and reliable (sharing) dissemination of the information
PedMHR: Needs of parents (2)

- Reliable reference information about their child’s condition and recommended therapies
  - Enable understanding
  - Promote compliance
  - Support the education of family members or other caregivers

- A parent-controlled health record may be a more feasible solution that could take advantage of and enhance collaboration with the Medical Home
PedMHR: PHR principles

• Parents are ultimately responsible for decisions about their children’s health
• Parents should have access to a reliable and complete record of their children’s health information
• Parents should have control and accountability over how these records are used and shared
• Information in the child’s health record should be understandable to parents and other caregivers

PedMHR: Methodology

• Objective
  – Identify (validate) the core features of an electronic record that would be perceived as helpful for families of CSHCN

• Approach
  – Attempt to understand the daily life of these children and their families
  – A small group of parents with extensive experience in advocating for improved care for their children, and who were passionate about improving systems of care for other families
  – Survey + focus group + literature review
  – Informal discussion with providers (U of Utah)
PedMHR: Participants

• 5 parents were ultimately identified, representing children with the following chronic conditions:
  – Down Syndrome (3 children)
  – Celiac Disease (1 child)
  – Cerebral Palsy (1 child)
  – Cystic Fibrosis (1 child)
  – Developmental delays not yet associated with a diagnosis (1 child)
  – The mothers were the primary caregivers

• Local groups involved with the effort
  – Utah State University’s Center for Persons with Disabilities, the Utah Down Syndrome Foundation, and the Utah Family Voices
PedMHR: Survey

• Each family received a survey designed to help identify their **computer literacy** and the level of **complexity of the care** required by their children
  – The survey was preceded by a brief description of the project, along with phone and email contacts that could be used to obtain further explanations
PedMHR: Focus group

• Families were invited to participate in a focus group discussion, organized as a mediated phone conference call
  – Each family described a typical day in their lives related to their disabled children
  – Each family was asked to elaborate on the potential value and desired features of an electronic parent-controlled health record
  – The session lasted almost 2 hours and was recorded after consent was obtained from each participant
PedMHR: Traditional features

- Track provider visits
- Ask questions prior to the next visit
- Review treatments, labs and tests ordered and medications prescribed
- Edit the record, but with a provider or care-coordinator validating its accuracy
- Link to friendly medication information
- “Make sure” that providers read what was entered in the record
- Award password protection and proxy rights to designated others
PedMHR: Core features

- Ease of accessing, recording, and organizing information about care
- Secure and customizable sharing of information with others in electronic or printed formats
- Focused links to relevant and reliable information and decision support
- Links to services and other resources, both locally and nationally
- Integration of voice recording, transcription, and indexing of visits with providers
- Integration of financial management tools
- Tools for creating and maintaining care plans, with reminders for parents and providers
• Conversations during physician visits are highly valued by patients/parents
  – However, much of what is said is missed or forgotten by parents after the visit, impairing compliance with treatment and depriving family members and other caregivers of the opportunity to understand the “what, why, and how” of the physician’s suggestions
PedMHR: Care plans

- Allow details of care needed by CSHCN to be recorded and shared with parents, providers, and designated others (e.g., family members, educators)
  - May also include **goals** against which progress can be measured, timelines able to trigger **reminders** of needed labs, appointments, or phone calls, and **links** to information, instructions, and data entry forms.
Parents often lament the need, particularly when their child is being admitted to a hospital, to repeat their “story” over and over to interns, residents, attendings, specialists, etc.

– Provide preformatted and customizable reports to alleviate much of this frustration and assure the accurate transmission of appropriate and current information

– Enable parents to ascertain who accessed the information and when
PedMHR: Links to information

- Access to information about their child’s condition, available services and other resources, educational interventions, growth and development, support groups, financial management, etc.
  - Integration with the MedHome Portal
  - Context-aware and data-driven “infobuttons”
PedMHR: Information sharing

• Enhance the ability of parents and physicians to share knowledge, information, and ideas
  – Parents of children with complex conditions often become experts in those conditions
  – Share resources using a variety of online tools (e.g., blogs, message boards, podcasts, wikis)
  – Critique existing resources and suggest/create new ones, individually or collaboratively
Managing family finances and negotiating the maze of insurance benefits can be a frustrating, nearly full-time job.
- Tools for tracking medical bills and payments, links to insurance companies, suppliers, and providers, and providing reports for use with tax preparation software.
PedMHR: Implementation

• How to get the record started?
  – Ask parents to gather the record (multiple sources)
  – Professional chart reviewer to create the record
  – PCP to review the initial record
  – Parent would subsequently maintain it, with PCP being responsible for periodic (6 months) reviews
(4) Challenges and opportunities
PedMHR: Interesting challenges

- Training (user literacy)
- Controlled proxy access by parents
- Parent-friendly content
- Integration with other electronic records
- Liability for providers
- Quality/validity of the data (annotations)
- Decision support for parents
Challenges

• Patients will want a **single** record that works with all their sites of care – institution-based?
• Support electronic data capture from **multiple** institutions (CCDs?) – **coordinated care**!
• Integrate **knowledge** sources on the Internet - specific knowledge bases and decision support systems (infobuttons?)
• Connect to **communities** of others with similar diagnoses – compare care experiences, therapies, and lessons learned
• Participate in clinical trials, post market pharmaceutical vigilance, or Public Health surveillance – **de-identified data**
• Potential to simplify **consent** models among producers and consumers of healthcare data

Challenges

- Standard data formats – adoption (and definition)
- Make electronic data available to patients
- Release of laboratory results directly to patients
- Availability of structured data (not scanned images of documents)
- Online consent processes (global research)
- Universal identifiers for patients

Medical Home challenges

• ARRA – not explicit, but includes care coordination, engaging patients and families, and population management

• Improvements are needed:
  – Clinical decision support
  – Registries
  – Team care
  – Care transitions
  – Personal health records
  – Telehealth technologies
  – Measurement

Adoption by patients with chronic conditions;
Patient data charting – detection of abnormal trends;
Notifications and appropriate message routing;
Measurement of quality and efficiency

Opportunities

- Hybrid (‘cloud’) models to enhance tethered PHRs
- Open platforms with standard APIs enabling ‘universal’ connectivity and competition
  - Revisit the overall HIT infrastructure
  - Widespread adoption driven by patients
- Profitable business models (transferable)
  - Reimbursement reform, brand loyalty, advertisements
- Overcome liability concerns for providers

Long-term vision

• Produce actionable information
  – Not an electronic ‘file drawer’
• Organize information
• Highlight trends
• Deliver useful feedback
• Enable consumers to live healthier lives, not simply manage their illness

The Power and Potential of Personal Health Records.
Acknowledgements

Chuck Norlin
Al Romeo
Gina Pola-Money
Jefferson Sheen
Families (mothers)
Utah Medical Home Portal team

CIRD team @ Partners HealthCare
Useful links

- Web site “The Power and Potential of Personal Health Records”
  - [http://www.rwjf.org/pioneer/product.jsp?id=49988](http://www.rwjf.org/pioneer/product.jsp?id=49988)

- Web site “myPHR”
  - American Health Information Management Association (AHIMA)
  - [http://www.myphr.com](http://www.myphr.com)

- Web site “Common Framework for Networked Personal Health Information”
  - Markle Foundation
  - [http://connectingforhealth.org/phti/index.html](http://connectingforhealth.org/phti/index.html)
More information about PHRs

- MyChildren's (Children's Hospital Boston)
  - [http://breezemsprod2.tch.harvard.edu/healthrecords/](http://breezemsprod2.tch.harvard.edu/healthrecords/)
- Shared Care Plan (Whatcom County, WA - Pursuing Perfection awardee)
  - [https://www.sharedcareplan.org/](https://www.sharedcareplan.org/)
- PassportMD
  - [http://www.youtube.com/watch?v=S04qDQ2uMOo](http://www.youtube.com/watch?v=S04qDQ2uMOo)
- Google Health
  - [http://www.youtube.com/watch?v=yNe6-p4G7Ik](http://www.youtube.com/watch?v=yNe6-p4G7Ik)
- Microsoft HealthVault
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- Dossia
  - [http://www.youtube.com/watch?v=Ta6RptfVK08&NR=1](http://www.youtube.com/watch?v=Ta6RptfVK08&NR=1)
- NoMoreClipboard
  - [http://www.youtube.com/watch?v=YaUg-9gJF6I](http://www.youtube.com/watch?v=YaUg-9gJF6I)
Thank you!

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