



# Personal Health Records

## Course VIII. Content for CPHIE

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Welcome to the Health IT Certification program on Health Information Exchange (HIE) Course on Personal Health Records. This is the fourth of the six courses in the Certified Professional in Health Information Exchange (CPHIE) track. Other courses in this track cover:

- V – HIE Goals and Governance
- VI – HIE Architecture
- VII – Data Stewardship
- IX – Telehealth and Home Monitoring
- X – Nationwide Health Information Network

# Introducing . . .



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# Objectives

- Upon completion of this course, participants should be able to:
  - Describe the impact of consumer empowerment on PHRs and their role in value-driven health care
  - Provide common definitions and attributes of PHRs
  - Utilize seminal research and thought leader experience to fit your HIE environment
  - Describe the dimensions of PHRs and supporting standards requirements
  - Identify policies and practices that overcome barriers and enable adoption of PHRs in HIE

While PHRs exist today outside of the HIE environment, certainly the federal government in its quest for value-driven health care views PHRs as integral to HIE. The objectives for this course address all aspects of PHR. HIEs may have greater influence in standards adoption for PHRs, for which there are entirely new dimensions of standards needed.

# Topics

Part 1. Consumer Empowerment (C.E.)

Part 2. PHR Definitions and Attributes

Part 3. PHR Dimensions and Supporting Standards

Part 4. Policies and Practices for PHRs in HIEs

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Topics covered in this Course describe the consumer empowerment movement overall and its impact on health care, acknowledge that while no standard definition for PHR exists there are a number of important attributes of PHRs, describe PHRs on various dimensions and how standards are supporting greater interoperability, and identify a number of policy and practice areas that should be addressed when sponsoring a PHR.

# Personal Health Records

## Part 1. Consumer Empowerment

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Consumer empowerment is a widespread movement, brought about largely through enhanced Internet tools. Consumer empowerment from social networking to the retail industry, from education to product differentiation, and more influences consumer empowerment in health care. Consumer empowerment has largely brought the concept of PHR to life, although there are numerous other characteristics of Generation V and the Connected Age of which the health care industry needs to be aware and to which it should acclimate itself.

# Content Part 1.

- Consumer Empowerment
- Health Care Consumerism
- Value Driven Health Care
- AHIC Use Case for Consumer Empowerment

**Is it PHR (a tool), or  
consumer empowerment  
(a collaborative form of health care)?**

**Health 1.0**

**Industrial  
Age**

**Information  
Age**

**Connected  
Age**

**Health 2.0**

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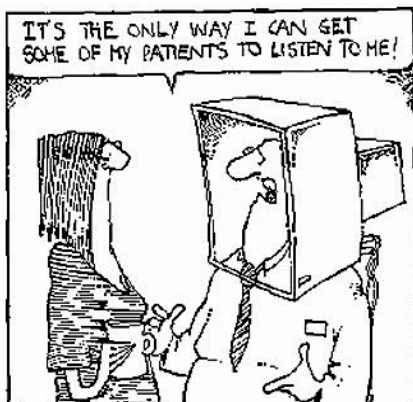
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Part 1 of this Course sets the context for PHRs – where consumer empowerment has virtually been the impetus for value-driven health care. The American Health Information Community, which has been the focal point for federal initiatives in health information technology (HIT), describes its PHR use case in the context of consumer empowerment.

# Consumer Empowerment

- A new market force that digitizes word of mouth
- Social networking and Web 2.0 enable people to connect and collaborate easily and productively, e.g.,
  - Blogs
  - Wikis
  - Podcasts
  - Vlogs
  - Technorati
  - LinkedIn
  - YouTube
  - MySpace



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## Generation V –Virtual Generation, members

- Are not defined by age, gender, geography, or social demographics
- Have a preference for use of digital media channels
- Believe in active participation in global communities
- Expect conversation not communication
- Learn in new, just-in-time ways

- Write
- Call
- Email
- Text

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ADD THIS BLOG TO MY Technorati FAVORITES



WIDGET MENU



Powered by AdaptiveBlue



Consumer empowerment in general is the investment of power or authority in those who purchase goods and services. Where in the past word of mouth has been a powerful determinant of customer relationships with suppliers, word-of-mouth without enhanced technological support still only reached a relatively small number of people and consumers' ability to influence research and development for innovation was relatively minimal.

Internet tools have truly changed not only consumerism, but have fostered a new generation of people who learn and interact differently than those in previous generations. For example, while some healthcare providers are still debating about whether to exchange email with their patients, many adults who have just become comfortable with managing email are finding that texting is now the preferred means of communication, and this will likely change as rapidly as the email to texting movement when even newer and more innovative ways emerge. Furthermore, with the ability to say what you want when you want and utilize digital media to meet personal preferences precisely, such communication is expected to be less directive and more interactive – communication is expected to be a conversation among members of Generation V. Consider only the clip from a visit to Technorati – who would think to combine general marketing, Zen habits, and wine advertisements with a posting for a freelance blog writer other than a member of Generation V!

## LIFE AS A HEALTHCARE CIO

EVERY DAY I EXPERIENCE LIFE IN THE WORLD OF HEALTHCARE IT, SUPPORTING 3000 DOCTORS, 18000 FACULTY, AND 3 MILLION PATIENTS. IN THIS BLOG I RECORD MY EXPERIENCES WITH INFRASTRUCTURE, APPLICATIONS, POLICIES, MANAGEMENT, AND GOVERNANCE AS WELL AS MUSE ON SUCH TOPICS SUCH AS REDUCING OUR CARBON FOOTPRINT, STANDARDIZING DATA IN HEALTHCARE, AND LIVING LIFE TO ITS FULLEST.

TUESDAY, OCTOBER 30, 2007

### Personal Health Records

The exact definition of a personal health record (PHR) is still evolving, but personal health records hold the promise to make patients the stewards of their own medical data. PHRs may contain data from payer claims databases, clinician electronic health records, pharmacy dispensing records, commercial laboratory results and patient self-entered data. They may include decision support features, convenience functions such as appointment making/requesting referrals/medication refill workflow, and bill paying. However, most PHRs are not standards-based and few support an easy way to transport records among different PHR products.

The current landscape of PHRs includes four basic models:

<http://geekdoctor.blogspot.com/2007/10/personal-health-records.html>



#### ABOUT ME



JOHN HALAMKA

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Health System, Chief Information Officer and Dean for Technology at Harvard Medical School, Chairman of the New England Health Electronic Data Interchange Network (NEHEN), CEO of MA-SHARE (the Regional Health Information Organization), Chair of the US Healthcare Information Technology Standards Panel (HITSP), and a practicing Emergency Physician.

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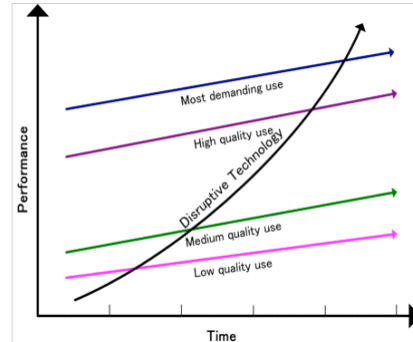
Perhaps John Halamka, MD, from whose blog this clip on PHRs was taken and who is chair of the Healthcare Information Technology Standards Panel (HITSP), is the epitome of a member of Generation V – reiterating that such members are not defined by age, gender, geography, or social demographics. (Perhaps this busy physician CIO is also a candidate for a ghost blog writer – though somehow we doubt that!)

A key point, however, is that as the growth of consumer empowerment accelerates and new technology arrives at an ever faster pace, it will become increasingly important for participants in an HIE to understand the latest technology, appreciate how those in whatever latest generation use the latest technology, and make adjustments to manage in changing times. It is not to suggest that everyone needs to become a daily blogger, but that you periodically check into who is saying what about your HIE and find out about what other HIEs are doing. Learning how to effectively use technology to convene meetings is a skill from which many in HIEs would benefit. It is not just the new document sharing or video technology itself that is important to learn, but how to manage the people, policies, and processes associated with using new technologies to aid meetings that will achieve important efficiencies. For example, one HIE started out meeting in person, requiring several participants to drive several hours. Once at the meeting, they often spent a good proportion of their time checking to make sure everyone had the latest documents under consideration, scrambling to scan the documents during discussion, and attempting to reconcile calendars for the next meeting. For every hour of quality meeting time, each participant was probably wasting an average of three hours that could have easily been saved through adoption of not even the latest information technology.

One CIO at a large hospital recently observed that differences were so striking between those newly hired into IT jobs and nurses on the units that it seemed like language translation was necessary. Although age is often – though not always – a major determinant of being facile with new technology, neither group is right or wrong, but interoperability between the groups at a people-level is probably as important as interoperability between information systems!

# Health Care Consumerism

- In general,
  - Extensive information sharing reduces product life cycles, contributing to disruptive innovation
  - Candid discussions about products and services may lead initially to increased competition; but access to information about how product creates customer satisfaction reduces differentiation and should increase overall quality
- Healthcare consumerism is a natural progression from consumerism in general. Employer demands for productive labor force and lower health care costs and government desire for value-driven health care leads to:
  - Demand from patients to participate as partners in health care, not be objects of it
  - Informed, activated patient expects prepared, proactive practice team
- Legislation for consumer rights (e.g., HIPAA, GLBA) provides transparency
- Coupled with consumer frustration with fragmentation of health care, shifting of costs (and responsibility) to consumers, and service demand exceeding supply of caregivers has led to:
  - Self-directed health care
  - Medical tourism
  - Personal health records
  - Support for health information exchange



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While conservative by nature, health care is not immune to consumerism, and growing health care consumerism is certainly a natural progression from consumerism in general. As social networking and Web 2.0 enable people to connect and collaborate easily and productively, sizable groups self-organize quickly around specific interests, and online collaboration tools enable them to coordinate action. While not all members of the health care industry belong to Generation V, those members of Generation V in the federal government, employers, health plans, and providers are certainly attempting to move the masses. Likewise, certainly not all patients or consumers of healthcare services are members of Generation V, and so not all are learning about or establishing expectations for their suppliers to adopt HIT.

But there is certainly a sufficient interest that many in position to influence change may utilize disruptive innovation to speed technology adoption further and faster. Such innovation has been evidenced in health care by employers promoting consumer-directed health plans, health plans promoting PHRs, individuals engaging in medical tourism, and more widespread interest among many stakeholders for HIE. Those advocating concerns about privacy and security in electronic health records have certainly used the technology to support their concerns. For example, a well orchestrated email campaign effectively derailed creation of a national data stewardship entity the federal government was proposing to ensure privacy within a nationwide health information network. Because this was interpreted to be a massive government database of personal health information by a core group of individuals, concern spread like wildfire throughout the privacy community. An interesting dichotomy on technology adoption! (Agency for Healthcare Research and Quality [AHRQ], National Health Data Stewardship Entity, Request for Information [RFI], *Federal Register*/Vol. 72, No. 106/Monday, June 4, 2007. Citizens' Council on Health Care response to RFI, July 21, 2007 at [www.cchconline.org/pdf/PubCommHealthDataStewardshipRFI\\_Final.pdf](http://www.cchconline.org/pdf/PubCommHealthDataStewardshipRFI_Final.pdf))

MN Community MEASUREMENT.



# Consumerism Case Study

## Diabetes

**YOUR ROLE**

**DOCTOR'S ROLE**

**MEASURE DETAIL**

**HOME PAGE**

**What is it?:** Diabetes is a disease that prevents the body from producing or properly using insulin, which is a hormone required for converting sugar, starches and other food into the energy needed for normal body function. Complications of diabetes include heart disease, kidney failure, amputations and blindness.

**Why is it important?:** About 20.8 million Americans—or about 7% of the U.S. population—are affected by diabetes. However, close to 30% of these people do not know they have it. Diabetes is the sixth leading cause of death in the United States. One in ten Minnesotans either have diabetes or are at high risk for developing the disease. The risk for cardiovascular disease and stroke is 2-4 times higher in people who have diabetes compared to those who don't. Sources: Centers for Disease Control and Prevention and Minnesota Department of Health

**Additional Resources:** [American Diabetes Association](#) | [Centers for Disease Control and Prevention](#) | [Diabetes Resources for Patients \(ICS\)](#) | [Minnesota Department of Health](#)

**What is this measuring?:** Optimal diabetes care. The percentage of patients with diabetes (Type I and Type II) from age 18 through 75 years who were continuously enrolled in their health plan during the measurement year (2005 dates of service) and reaching all of the following 5 treatment goals: (1) Hemoglobin A1c (HbA1c) less than or equal to 7.0%; (2) Blood Pressure less than 130/80 mmHg; (3) LDL-C less than 100 mg/dl; (4) Daily aspirin use ages 41-75; and (5) Documented tobacco free. The data collected for this measure are from health plan claims and medical record review.

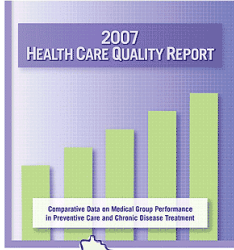
**Legend:** ★ = Below Average • ★★ = Average • ★★★ = Above Average • █ = Diabetes Group Average: 10% (2006)

| Rating | Provider Group                               | Rate* |
|--------|--|-------|
| ★★★    | <a href="#">HealthPartners Medical Group</a> | 15%   |

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An interesting case study of health care consumerism is the Minnesota Community Measurement project, which, since 2005, has been using HEDIS data supplied through claims and supplemented with chart data to report very specific information about clinic outcomes. The result is that each clinic has reported its outcomes on the various measures. The intent was to make consumers more informed about quality of care.

# What Has Been the Result?

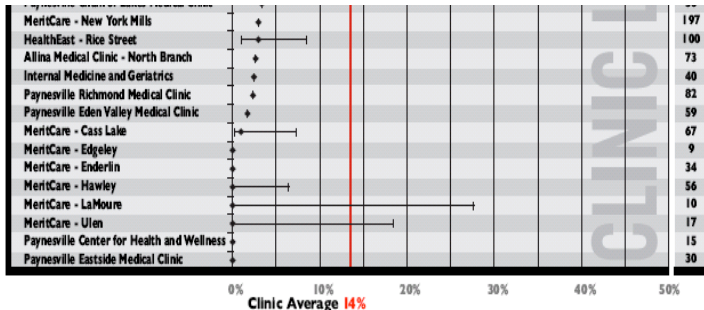
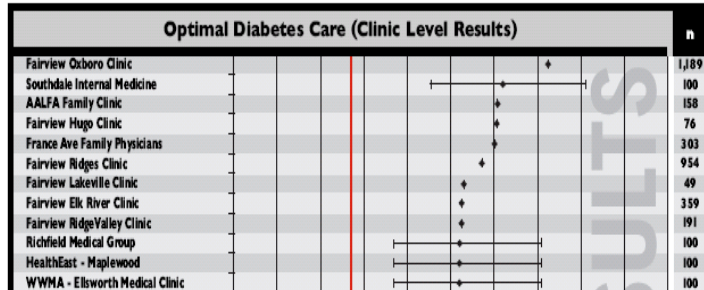


www.mnhealthcare.org

Competition  
Among  
Clinics!

MN Community Measurement 2007 Health Care Quality Report

December 2007



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Interestingly, the result of the Minnesota Community Measurement project has been not only consumer empowerment, but perhaps an even more important result has been competition among clinics. The clinics viewing their findings are pushing the bar to achieve increasingly better results – certainly a desirable outcome of the project!

### Health Care "System"?

The health care "system" in America is not a system. It's a disconnected collection of large and small medical businesses, health care professionals, treatment centers, hospitals, and all who provide support for them. Each player may have its own internal structure for gathering and sharing information, but nothing ties those isolated structures into an interoperable national system capable of making information easily shared and compared.

### Transparency Leads to Change

Transparency is a broad-scale initiative enabling consumers to compare the quality and price of health care services, so they can make informed choices among doctors and hospitals.

In cooperation with America's largest employers and the medical profession, this initiative is laying the foundation for pooling and analyzing information about procedures, hospitals, and physician services. When this data foundation is in place, regional health information alliances will turn the raw data into useful information for consumers.

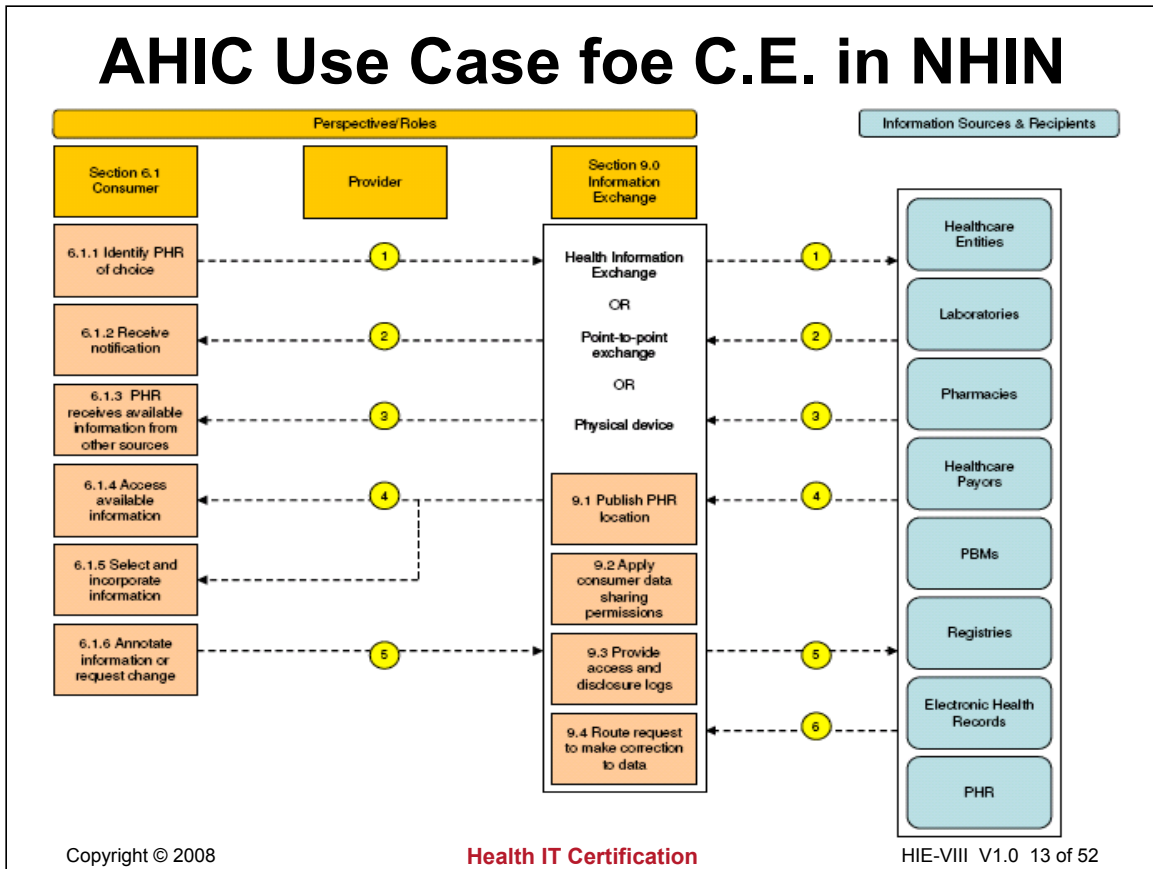
#### ▪ **Four Cornerstones**

- Connecting systems, standards and support for e-health
- Measuring and publishing quality data
- Measuring and publishing price data
- Creating positive incentives

#### ▪ **Breakthrough areas:**

- Consumer empowerment
- Chronic care
- Biosurveillance
- Electronic health records

The federal government has been keenly interested in consumer empowerment, identifying it as one of four breakthrough areas in its strategic goals. We have emphasized the federal government's interest in value-driven health care throughout this program because it is the key economic factor driving HHS as it realizes the issues with the current health care system and is encouraging transparency to lead to change. The four cornerstones approach of connecting systems, measuring and publishing quality and price data, and creating positive incentives is banking on consumer empowerment to influence the health care marketplace. It is consumer empowerment, then, that is driving PHRs within a connected system approach (an HIE and ultimately a nationwide health information network [NHIN]).



The American Health Information Community (AHIC) is the federal government’s focal point for developing its HIT initiatives. It is a federal advisory body, chartered in 2005 to make recommendations to the Secretary of the U.S. Department of Health and Human Services (HHS) on how to accelerate the development and adoption of HIT and to help advance efforts to achieve President Bush’s goal for most Americans to have access to secure electronic health records by 2014. Plans are now underway to establish a successor to the AHIC as a public-private partnership based in the private sector by Fall 2008. The AHIC successor will be independent and sustainable and will bring together the best attributes and resources of public and private entities. This new public-private partnership is expected to develop a unified approach to realize an effective, interoperable nationwide health information network (NHIN) that supports the health and well-being of all people in the U.S.

One of the first three use cases AHIC proposed was for consumer empowerment (C.E.) – the other two being electronic health records (EHR) and biosurveillance. This use case illustrates the scope of the AHIC’s vision for consumer empowerment and how HIE plays a pivotal role in connecting consumers with their health information from multiple sources.

# **Personal Health Records**

## **Part 2. PHR Definitions and Attributes**

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So with keen interest in consumer empowerment, PHRs have gotten a significant boost. Part 2 of this Course focuses on what a PHR may be, what attributes are generally associated with PHRs, and what services an HIE may provide to further support PHRs as well as how HIEs may use PHRs to support their information flow.

## Content Part 2.

- No Standard Definition
- HL7 Overarching Themes for PHR-System Functional Model
- ASTM Continuity of Care Record
- HITSP Consumer Empowerment Interoperability Specification Attributes
- Other Sources of Definition
- Legal Health Record

Specifically, Part 2 summarizes information from key organizations and thought leaders. In addition to enabling an HIE to define its view of PHR and identify the attributes it wants to support, this Part of the Course serves to identify resources for additional information that may be tapped for setting policy and practice.



# No Standard Definition

- PHR-System Functional Model, DSTU, November 2007
- “The HL7 PHR-S Functional Model does not attempt to define the PHR, but rather identifies the features and functions in a system necessary to create and manage an effective PHR.”
- HL7 makes a clear distinction between a PHR and a PHR System:
  - PHR is the underlying record that the software functionality of a
  - PHR-System maintains
  - This distinction is consistent with its EHR System Functional Model

|                            |        |  |
|----------------------------|--------|--|
| Personal Health            | PH.1.0 | Account Holder Profile                                 |
|                            | PH.2.0 | Manage Historical Clinical Data And Current State Data |
|                            | PH.3.0 | Wellness, Preventive Medicine, and Self Care           |
|                            | PH.4.0 | Manage Health Education                                |
|                            | PH.5.0 | Account Holder Decision Support                        |
|                            | PH.6.0 | Manage Encounters with Providers                       |
| Supportive                 | S.1.0  | Provider Management                                    |
|                            | S.2.0  | Financial Management                                   |
|                            | S.3.0  | Administrative Management                              |
|                            | S.4.0  | Other Resource Management                              |
| Information Infrastructure | IN.1.0 | Health Record Information Management/                  |
|                            | IN.2.0 | Standards Based Interoperability                       |
|                            | IN.3.0 | Security   |
|                            | IN.4.0 | Auditable Records                                      |

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Health Level Seven (HL7) is one of several American National Standards Institute (ANSI) accredited standards developing organizations (SDO) operating in the healthcare arena. HL7 produces standard specifications, or protocols, for the clinical and administrative data domain (while other SDOs address such standards for as pharmacy, medical devices, imaging, or financial and administrative transactions).

HL7’s overall mission is to provide standards for interoperability that improve care delivery, optimize workflow, reduce ambiguity, and enhance knowledge transfer among stakeholders, including healthcare providers, government agencies, the vendor community, fellow SDOs, and patients. HL7’s strategies are to develop coherent, extendible standards that permit structured, encoded health care information of the type required to support patient care, to be exchanged between computer applications while preserving meaning. It utilizes a formal methodology to support the creation of its standards from the its Reference Information Model (RIM). HL7 also believes it plays an important role in educating the healthcare industry, policy makers, and the general public concerning the benefits of healthcare information standardization generally and HL7 standards specifically. It collaborates with other SDOs and national and international sanctioning bodies (e.g. ANSI and ISO), in both the healthcare and information infrastructure domains to promote the use of supportive and compatible standards; and with HIT users to ensure that HL7 standards meet real-world requirements and appropriate standards development efforts are initiated to meet emergent requirements.

As such, HL7 developed an EHR-System Functional Model Draft Standard for Trial Use (DSTU) in 2003 which became fully ANSI accredited in 2007. At that time, it recognized the need for a similar model for PHRs, and developed – in similar format – a PHR-System Functional Model, DSTU. While it (as do many other organizations) argues that there is no standard definition of a PHR, its model identifies the features and functions in a system necessary to create and manage an effective PHR. Its high level model is illustrated here.

## HL7 Overarching Theme for PHR-S

- Patient centric tool controlled, for the most part, by the individual. Immediately available electronically, able to link to other systems, either “pull-push” or “push-pull”
- Helps an individual maintain a longitudinal view of health history, and may be comprised of information from providers and health plans, as well as from individual
- Helps collect behavioral health, public health, patient-entered and patient-accessed data (including medical monitoring devices), medication information, care management plans. Connected to providers, laboratories, pharmacies, nursing homes, hospitals, etc.
- Captures and maintains demographic, insurance coverage, and provider information; provides ability to capture health history in the form of a health summary, problems, conditions, symptoms, allergies, medications, laboratory and other test results, immunizations and encounters; and makes available personal care planning such as advance directives, care plans, and advice (diet, exercise, disease management)
- Must be secure and have appropriate identity and access management, and use standard nomenclature, coding, and data exchange standards for interoperability
- Optional features: secure messaging, graphing test results, patient education, guideline-based reminders, appointment scheduling, drug-drug interactions, formulary management, cost comparisons, document storage, and clinical trial eligibility
- “The effective use of a PHR-S is a key point for improving healthcare in terms of self-management, patient-provider communication and quality outcomes.”

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HL7's overarching theme for a PHR-System is summarized here. A key message HL7 incorporates in its PHR-S Functional Model, DSTU, is that “the effective use of a PHR-S is a key point for improving healthcare in terms of self-management, patient-provider communication, and quality outcomes.” Because it is a draft standard – which means it is put forth for trial use and subsequent refinement, those utilizing the model are encouraged to participate in providing feedback to HL7 – does it “address all features and functions in a system necessary to create and manage an effective PHR,” as billed? Are all the right stakeholders at the table? All SDOs tend to suffer from the inability to garner full participation from every stakeholder interest group. It needs to hear from consumers themselves, those forming HIEs, the health plan and employer community, as well as the provider community – and the HIT vendors who supply products and services.



## E2369-05 Standard Specification for Continuity of Care Record (CCR)

- Defines core data set of most relevant administrative, demographic, and clinical information about a patient's healthcare.
  - Provides a means for one healthcare practitioner, system, or setting to aggregate all of the pertinent data about a patient and forward it to another practitioner, system, or setting to support the continuity of care \*
  - CCR may be prepared, displayed, and transmitted on paper or electronically.
    - When prepared in electronic format, strict adherence to an XML schema and accompanying implementation guide is required to support interoperability
    - This enables preparation, transmission, and viewing in multiple ways, such as in a browser, secure email, PDF file, HTML file, word processing document, or as an element in a HL7 message or **HL7 CDA complaint document**
- The specification notes that
  - CCR is an outgrowth of the Patient Care Referral Form mandated by the Massachusetts Department of Public Health for use primarily in inpatient settings
  - The CCR XML is not a persistent document, and not a messaging standard
  - Using XML schema, EHR systems will be able to import and export CCR data to enable automated healthcare information transmission, and interchange of CCR data between otherwise incompatible EHR systems

\* Many PHRs are being designed to meet CCR specification



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ASTM International is one of the largest and probably the oldest voluntary SDO in the world, developing standards for materials, products, systems, and services. (For example, many may have seen the ASTM D4236 designation on highlighters – which specifies conformance with precautionary labeling for commercial art materials.) Originally known as the American Society for Testing and Materials (ASTM), ASTM International was formed over a century ago (in 1898), when a forward-thinking group of engineers and scientists got together to address frequent rail breaks in the burgeoning railroad industry. Their work led to standardization on the steel used in rail construction, ultimately improving railroad safety for the public. As the century progressed and new industrial, governmental, and environmental developments created new standardization requirements, ASTM responded with consensus standards for issues ranging from safety in recreational aviation, to fiber optic cable installations in underground utilities, to homeland security.

ASTM Committee E31 on Healthcare Informatics develops standards related to the architecture, content, storage, security, confidentiality, functionality, and communication of information used within healthcare and healthcare decision making, including patient-specific information and knowledge. Established in 1970, E31 is perhaps best known today for its E2369 Standard Specification for Continuity of Care Record (CCR), initiated by the Massachusetts Medical Society and sponsored further by the Healthcare Information Management and Systems Society (HIMSS) and other organizations. The specification provides for core content to be transferred among referring providers. It has subsequently been widely adopted as core content for PHRs. Although the specification is suitable for any media, it provides an implementation guide for using the CCR XML schema for generation of a standards-compliant CCR.



## HITSP Consumer Empowerment Interoperability Specification

- HITSP Consumer Empowerment and the Consumer Access to Clinical Information **Use Cases** describe active involvement of consumers (i.e., individuals) in managing their healthcare and gaining benefits of having their health information in a format easily accessible to them. This includes having a personal health record (PHR) system to track healthcare information, insurance, family history, medications, and enabling:
  - Querying other organizations for data and matching to consumer
  - Accepting “batch” data from other organizations and matching to appropriate consumers
  - Accessing, viewing, and sharing registration summaries and medication histories
  - Ability for consumer to retrieve, store, graph and share laboratory test results
  - Ability to access results, conditions, allergies, and diagnosis codes in layperson terms
  - Ability to identify and maintain a list of all providers involved in the care of a specific patient, to use the provider list to communicate information about the patient to all or selected providers and forward the list of providers to another provider or entity
  - Ability for a consumer to identify those providers which are permitted to access information in the consumers' PHR, and which of those data they are permitted to access and to communicate the consumer's decisions to other entities which also hold data about the consumer
  - Ability for a consumer to request, consolidate, and access audit log information from multiple sources to create logical views of access to their information
  - Ability to describe a consumer's access decisions using information which can be communicated among systems involved in information exchange

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The Healthcare Information Technology Standards Panel (HITSP) is a multi-stakeholder coordinating body convened under federal government contract as one of the AHIC initiatives. Its purpose is to identify interoperability standards to facilitate exchange of patient data. Utilizing the AHIC Consumer Empowerment Use Case, it developed an interoperability specification (I.S.) that describes the existing standards and specifications that will satisfy the requirements imposed by the AHIC use case, including identifying where there are gaps and overlaps. It has included attributes of PHRs in its Consumer Empowerment Interoperability Specification.

# Other Sources of Definition

- **American Health Information Management Association (AHIMA)**
  - “The PHR is an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information, 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”
- **Centers for Medicare and Medicaid Services (CMS)**
  - “A PHR is a confidential and easy-to-use tool for managing information about your health. It is usually an electronic file or record of your health information and recent services... You control how the information is used and who can access it. They are usually used on the Internet so you can look up your information wherever you are.”
- **Connecting for Health, Markle Foundation**
  - “PHRs encompass a wide variety of applications that enable people to collect, view, manage, or share copies of their health information or transactions electronically. Although there are many variants, PHRs are based on the fundamental concept of facilitating an individual's access to and creation of personal health information in a usable computer application that the individual (or a designee) controls”
- **National Committee on Vital and Health Statistics**
  - “PHRs are broadly considered as a means by which an individual's personal health information can be collected, stored, and used for diverse health management purposes.” “There is no uniform definition, and the concept continues to evolve. Lack of consensus makes collaboration, coordination, and policymaking difficult.” NCVHS concluded that “it is not possible, or even desirable, to attempt a unitary definition at this time.” However, it did believe it is useful to identify attributes.

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Other organizations engaged in promoting PHRs, educating consumers, and identifying policy implications are:

The American Health Information Management Association (AHIMA), whose members are generally considered the legal custodian of health records in hospitals. HIM professionals are trained to ensure the quality, privacy, and integrity of health records in any form. They ensure that The Joint Commission Information Management standards are consistently applied. [www.AHIMA.org](http://www.AHIMA.org) provides members and non-members a wealth of information about health information in general, and EHRs, PHRs, and HIE specifically. It also sponsors, with its Foundation of Record Education (FORE), a consumer website describing PHRs and supplying both paper forms and links to electronic PHR vendors ([www.myPHR.com](http://www.myPHR.com)).

CMS is major proponent of PHR use. While it does not currently offer a PHR to its beneficiaries, it is engaged in studying PHR use, and provides the public with definition, information about PHR privacy and security, how to choose a PHR, and information about its pilot testing. See [www.medicare.gov/PHR/Overview.asp](http://www.medicare.gov/PHR/Overview.asp) and [www.medicare.gov/CMSandPHR.asp](http://www.medicare.gov/CMSandPHR.asp) for additional information.

Connecting for Health is a public-private collaborative with representatives from more than 100 organizations across the spectrum of health care stakeholders. Its purpose is to catalyze the widespread changes necessary to realize the full benefits of health information technology (HIT), while protecting patient privacy and the security of personal health information. It observes that its “most basic agenda is to improve health and the health care system for patients and consumers through connectivity and information sharing.” It is led and operated by the Markle Foundation with additional financial support from the Robert Wood Johnson Foundation. Connecting for Health has also put a stake in ground for a definition of PHR: [connectingforhealth.org/commonframework/docs/P9\\_NetworkedPHRs.pdf](http://connectingforhealth.org/commonframework/docs/P9_NetworkedPHRs.pdf)

Finally, the National Committee on Vital and Health Statistics (NCVHS) is a statutory public advisory body to the U.S. Department of Health and Human Services, providing advice to the Secretary of HHS on health data, statistics, and national health information policy, including on the implementation of the Administrative Simplification provisions of HIPAA. It has weighed in on PHRs – also expressing concern that there is no standard definition, but advising on important attributes at: <http://www.ncvhs.hhs.gov/0602nhiirpt.pdf>

# Legal Health Record



- **Record** (HIPAA) “any ... grouping of information that includes PHI ... maintained, collected, used, or disseminated by/for covered entity”
- **Designated record set** (HIPAA) “means medical and billing records maintained by covered entity ... Used ... to make decisions about individuals”
- **Legal health record** (AHIMA) “generated at or for a healthcare organization as its business record and is the record that will be disclosed upon request. It does not affect the discoverability of other information held by the organization”
- **Hybrid record** refers to a system of health records with functional components that:
  - Include both paper and electronic documents and data
  - Use manual and electronic processes
- **Metadata** are data about data, and underlying applications and programs
- **Disclosure** (HIPAA) is “release, transfer, provision of access to ... information outside the entity holding the information.” Disclosure is performed in response to valid authorization or as required by law
- **Discovery**: compulsory disclosure at pretrial
  - “**E-Discovery**” refers to Amendments to Federal Rules of Civil Procedure and Uniform Rules Relating to Discovery of Electronically Stored Information
  - Disputes concerning discovery and use at trial are resolved through court rulings on discovery motions
- **Spoilation of evidence doctrine** requires holding from destruction records of pending or potential litigation (“Litigation hold”)
  - Destroying such a record may be viewed by courts as obstruction of justice in a criminal case
  - Courts may impose sanctions for destroying records, e.g., not allowing documents at trial, special jury instructions, financial sanctions, fines, imprisonment, or new lawsuit
- **Best evidence rule** states a preference for “original” of a record; but rules of evidence deem printout or other readable output shown to reflect the data accurately as an original

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In their role as custodians of health records for their facilities, AHIMA members are responsible for responding to requests for release of information, including to subpoenas and court orders for health records. As such, AHIMA has been instrumental in defining the legal health record, especially in response to the Amendments to the Federal Rules of Civil Procedure and Uniform Rules Relating to Discovery of Electronically Stored Information (commonly referred to as E-discovery) issued in August 2007 (and for which many states are modeling their own state versions). Not to digress too far from PHRs, but it is important to place the concept of PHR in the context of other sets of health information, especially as may be related to E-discovery.

E-discovery entails obtaining new information in new forms from new places and new sources and using it in a new manner. Approaches include:

- Computer forensics to analyze source of electronic data to determine if data were accessed, destroyed, or fabricated. This is a particularly important element relating to provision of access to EHR data via a patient portal or other form of PHR. Many providers express concern that consumers may be able to alter their business records; or that the individual may have altered data supplied to their own PHR – unintentionally or intentionally. Security controls to address data integrity are critical, and they must include not only access controls but the ability to track and regularly monitor who has accessed information.
- Searching for, gathering, reviewing, analyzing, and using large amounts of relevant information in routine litigation is another strategy used in E-discovery and is also a concern of providers concerned that EHRs can and do generate much more information about the timeliness of entries, changes to entries, etc.
- Focused search for electronically stored information relevant to a specific case, such as cell phone records, and email or instant messaging of key participants – again, issues to address as consumers desire more messaging with their providers, health plans, and others.

While E-discovery may be alarming to some within the health professions, it can shore up the necessary security controls needed not only in support of EHRs but PHRs and both as used in HIE.

## Attributes of PHR

### Attributes of PHR from Personal Health WG:

- Each person controls his or her own PHR
- PHRs contain information from one's entire lifetime including information from all health care providers
- PHRs are accessible from any place at any time
- PHRs are private and secure
- PHRs are transparent. Individuals can see who entered each piece of data, where it was transferred from, and who has viewed it
- PHRs permit easy exchange of information

### Networked PHRs Help Meet IOM Design Rules for safe, effective, patient-centered, timely, efficient, and equitable healthcare system:

- Care based on continuous healing relationships
- Customization based on patient needs and values
- Patient as the source of control
- Shared knowledge and free flow of information
- Evidence-based decision-making
- Safety as a system property
- Need for transparency
- Anticipation of needs
- Continuous decrease in waste
- Cooperation among clinicians

- When you see a new doctor, do you scratch your head to remember all your health data as you fill in registration forms?  
– U.S. spends \$125 B annually on unnecessary paperwork
- Are you confident you get safe, coordinated care?  
– 42% of American say someone in their family has been victim of medical error
- In an accident, do you think ED could get vital information on you?  
– 25% of Americans think so, but almost no ED can
- Do specialists ask you to have tests performed by your regular doctor repeated?  
– Experts say up to 10% of tests performed are unnecessary or duplicative
- Do you think your doctor keeps your medical information on computer?  
– 40% of Americans think so, but only (5%, 2003) do

Connecting for Health has incorporated the concept of PHR in its considerations for ways to catalyze the widespread changes necessary to realize the full benefits of health information technology (HIT), while protecting patient privacy and the security of personal health information since its Personal Health Working Group identified attributes of PHRs in 2003. The result of this and other working groups was its Common Framework, that helps health information networks share information among their members and nationwide while protecting privacy and allowing for local autonomy and innovation. The Common Framework consists of a set of 17 mutually-reinforcing technical documents and specifications, testing interfaces, code, privacy and security policies, and model contract language. It was developed by experts in information technology, health privacy law, and policy, and has been tested since mid-2005 by Connecting for Health prototype teams in three states: California, Indiana, and Massachusetts. Its Common Framework for Networked Personal Health Information, one of the 17 specifications, was released in December 2006, and adds to the attributes the notion that, to meet the vision of a health care system as put forth by the Institute of Medicine in its landmark *Crossing the Quality Chasm* report in 2001, there needs to be an advanced role for patients and their families. (<http://www.connectingforhealth.org/commonframework/index.html>)



## Initial Framework of PHR and PHR Systems Attributes

- Scope and nature of content
  - Some PHR systems just have consumer health information, personal health journals, or information about benefits and/or providers, but no clinical data about the individual.
  - Some PHR systems have clinical information. Of these, some are disease specific, some include subsets of information such as lab reports, and some are comprehensive.
- Source of information
  - Data in PHR systems may come from the consumer, patient, caregiver, healthcare provider, payer, or all of these.
  - Some PHR systems are populated with data by EHRs.
- Features and functions
  - PHR systems offer a wide variety of features, including the ability to view personal health data, exchange secure messages with providers, schedule appointments, renew prescriptions, and enter personal health data; decision support (such as medication interaction alerts or reminders about needed preventive services); the ability to transfer data to or from an EHR; and the ability to track and manage health plan benefits and services.
- Custodian of the record
  - The physical record may be operated by a number of parties, including the consumer or patient, an independent third party, a healthcare provider, an insurance company, or employer
- Data storage
  - Data may be stored in a variety of locations, including an Internet-accessible database, a provider's EHR, the consumer/patient's home computer, a portable device such as a smart card or thumb drive, or a privately maintained database.
- Technical approaches
  - Current PHRs and PHR systems are generally not interoperable (with the exception of the PHRs that are "views" into the EHR) and they vary on how they handle security, authentication, and other technical issues.
- Party controlling access to the data
  - While consumers or patients always have access to their own data, they do not always determine who else may access it. For example, PHRs that are "views" into a provider's EHR follow the access rules set up by the provider. In some cases, consumers do have exclusive control.

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As a result of its landscape survey, NCVHS made a number of recommendations on PHRs to HHS – for:

1. Consensus framework to characterize PHRs.
2. Education for consumers as well as providers and other stakeholders on benefits and risks of PHRs.
3. Education about privacy, including privacy policies and practices of PHR system vendors and the enumeration of uses and disclosures that may be made of personally identifiable health information held in PHRs (see CPHIE Course VII on Data Stewardship).
4. Best practices with respect to privacy policies and practices.
5. Privacy notices and express consent of consumer for use and disclosure of information from PHR in HHS-sponsored PHR activities.
6. Voluntary adoption of strict privacy policies and practices by entities not covered by HIPAA.
7. Assessment of other issues associated with privacy and other consumer protections and address in appropriate actions.
8. Security standards framework, including providing consumers with a terms and conditions of use of PHRs, ensuring audit functionality, use of industry-standard security and authentication schemes, and functionality that provides a consumer with ability to control who access the PHR.
9. Adoption of security protections with HIPAA security rule in any HHS-sponsored pilot project and HHS contracts.
10. Addressing gaps in standards for interoperability.
11. Encouragement for consistency between EHR and PHR standards
12. Standard data sets for PHRs.
13. Adoption of standard data content and exchange standards for any HHS-sponsored pilot projects and contractual relationships that CMS undertakes with entities intending to utilize CMS data in PHR systems.
14. Voluntary adoption of data content and exchange standards that are based on standards accepted for EHRs for private sector PHR vendors and organizations.
15. Assessment of role for federal government in promoting benefits of PHRs.
16. Considerations for underserved populations that may limit dissemination of PHR systems. Specifically also address health literacy issues that could limit use of PHR by the most vulnerable populations.

# **Personal Health Records**

## **Part 3. PHR Dimensions and Supporting Standards**

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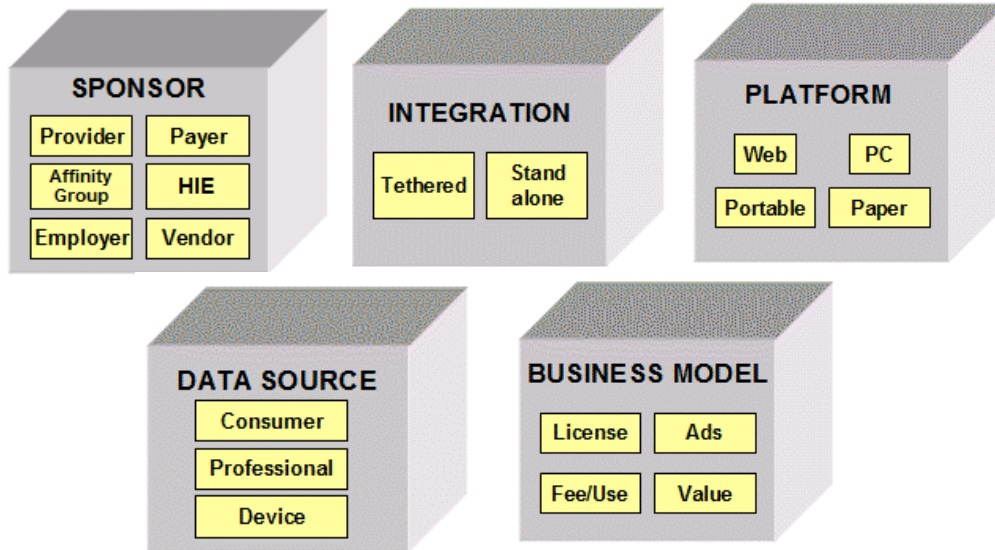
Because there are multiple ways PHRs may come into existence and be used within an HIE, it is important to fully understand all dimensions that characterize PHRs in any form. Even without a standard, unitary definition of PHR – which, as NCVHS suggests, may not be feasible or necessary, there are supporting standards that should be addressed irrespective of the dimensions any given PHR incorporates.

## Content Part 3.

- Sponsors
- Integration
- Platforms
- Data Sources
- Business Models
- HITSP Consumer Empowerment Interoperability Specification Standard Constructs
- ASTM and HL7 CCR/CCD

Topics covered in Part 3 explore the various dimensions of PHRs and standards available for use.

# PHR Dimensions



- Many PHRs are a blend of several categories on each of the dimensions

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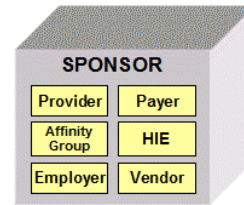
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While characterizing dimensions is also not standardized, the Markle Foundation's Connecting for Health offered a version of PHR dimensions that suggests there are at least five if not other dimensions that characterize PHRs. Any given PHR may be a blend of several categories on each of the dimensions – so, for example, a given provider's PHR may be "tethered," or integrated with its EHR or other HIT, but may support not only a patient portal through the Web but the ability for the patient to receive a download of information onto a CD, flash drive, or other portable device and maybe even receive a paper copy if necessary. The source of the information may only be the provider, or it could multiple professionals, consumer, and their caregivers. Some PHRs may also support connectivity with medical devices (see CPHIE IX: Telehealth and Home Monitoring). Finally, of course, there are various business models.

It should also be recognized that there is the potential for any given individual to have multiple PHRs – perhaps from multiple sponsors and/or one sponsor and their own adoption of a vended product that is completely standalone from any sponsor.

# Sponsors

- **Provider**, may supply
  - Generic patient education
  - Patient-friendly summary
  - Some or all contents of EHR
  - Access to variety of services (e.g., appointment scheduling, messaging)



- **Payer**
  - Often populates (PHR and/or EHR) with claims data: diagnosis codes and/or their interpretation as a problem list; medication list
  - May include disease management, pharmacy benefits management



- **Affinity Group**
  - Serves the need of a specific population, geographic area, disease, age, etc.



- **HIE**
  - PHR may be convening structure, integrating factor, or value-add

- **Employer**
  - Often includes health risk appraisals, lifestyle programs, information about insurance offerings, hyperlinks to company intranet



- **Vendor direct to consumer**
  - Direct data entry into templates, ability to upload files and scanned images; hyperlinks to Internet websites



- **Sponsors often supply a PHR through a contract with a PHR vendor**

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Many different organizations may sponsor PHR use, and, of course, individuals may sign up online for a PHR through a vendor without any other sponsorship. Many more individuals maintain some form of PHR on paper. Probably the most common sponsors of electronic PHRs today are individuals themselves and providers (see slides later for examples).

Payers and employers have become very actively engaged in PHRs. MyHealthVet is an example of a payer-sponsored PHR from the Veterans Health Administration. Vendors are developing PHR products for insurers that include for their members: comprehensive medication records, medical history, test results, contact information, and printer-friendly health record reports. For the administrator of the health plan, the PHR vendors supply various tools, such as utilization and performance data by user type, employer group, and population for each program component; data import functions that support batch loading of third party data; and data export functions that provide access to all clinical data for detailed analysis of outcomes and integration with claims data for consolidated reporting ([www.pdhi.com/webnew/products/ConXushealth.asp](http://www.pdhi.com/webnew/products/ConXushealth.asp)). Employers, sometimes only in conjunction with a PHR vendor and other times with providers and/or health plans, are offering employees PHRs. Dossia is one of the most widely publicized efforts, where a consortium of large employers (e.g., AT&T, BP America, Intel Corporation, Wal-Mart) united in their goal of providing employees, their dependents, retirees, and others in their communities with an independent, lifelong health record. Employee participation is completely voluntary and individuals have complete control over who sees their information. Information is continually updated and available to individuals for life even if they change employers, insurers, or doctors. The Dossia project has been endorsed by the American Academy of Pediatrics, American Academy of Family Physicians, Centers for Disease Control and Prevention, and National Association of Manufacturers.

Affinity groups, serving the need of a specific group, have also emerged as important – especially for those with chronic conditions or unusual diseases. The Pink Key is an example of a PHR product tailored to those with breast cancer. More will be discussed on PHRs in HIE specifically, but the factor to consider with respect to HIE is that the consent directives that some HIEs are including may be considered a form of PHR, or at least consumer empowerment.

# BlueCross BlueShield Case Study

- BCBS-South Carolina
  - Claims-fed PHR interfaces with the Plan’s disease and maternity management nurses
  - Allows Plan nursing staff to “IM” members, push Healthwise content, and walk them through health risk appraisal, if necessary
  - Claims content auto-generates Healthwise content to member’s PHR where indicated
- BCBSA-AHIP PHR Project
  - Payer-based PHR data transfer standard framework
    - 16 standard PHR data domains
    - Map identifying data source
    - Data dictionary
    - Implementation guide and operating rules
    - Plan-to-plan standard for transferring PHR information (consistent with AHIC/HITSP/HL7/X12), making plan PHRs portable as members move

## •“Information Therapy” by



- Example of a consumer health content company, providing health information tailored to consumers that can be used by hospitals, health plans, disease management companies, etc. to tailor delivery of health information.

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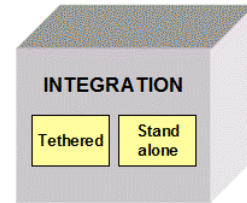
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BlueCross BlueShield Association of South Carolina (BCBS-SC) is an example of a health plan that has had considerable success using a PHR that is integrated with its disease management program and enables consumer health content to be coordinated directly in the “conversation” with their members.

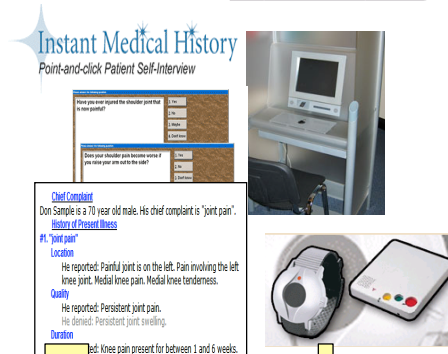
BCBS-SC has also pioneered in a number of other information technology uses and support for various consumer empowerment-related trends. It is the first such health plan to support an affiliation with Bumrungrad Hospital in Thailand for medical tourism. *Patients Beyond Borders* that tracks such activity reports that more 150,000 American traveled abroad for health care during 2006 and that is expected to double by 2008.

BlueCross BlueShield Association (BCBSA) and America’s Health Insurance Plans (AHIP) has also released a model for PHRs that, when fully implemented, will enable the various Plans’ PHRs to be portable. It is a Web-based tool that includes a customer’s insurance claims, immunization records, medication records, and other health information. They anticipate that patients will be able to enter information into their PHRs, and receive information from pharmacies, laboratories, and medical providers. There are 13 data domains (patient information, family history, physiological data, encounters, medication, immunization, provider contacts, facility contacts, health risk factors, advance directives, alerts, health plan data, and plans of care) that were evaluated by focus groups as being important for management of chronic conditions that require both prescription medications and the use of more than one physician, and for those who are aware they are at risk for diabetes, heart disease, or cancer.

# Integration



- **Tethered** (a.k.a., portal)
  - PHR that is integrated with another information system
    - Provider's practice management system
    - Provider's EHR
    - Other sponsor (e.g., PBM for formulary)
    - Monitoring device
  - May provide secure messaging, support data entry only for provider consumption, enable viewing and not downloading, or be fully interactive and enable input
  - May be "owned" by sponsor; or subscription to a vendor PHR
- **Standalone**
  - Not integrated with any other system
  - Typically reliant on individual data entry
  - May receive electronic feed of data as directed by individual from other sources



## Examples



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In general, PHRs are either tethered or standalone. Some of the key issues with the tethered model include:

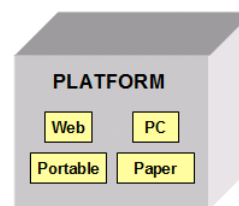
- How comprehensive are they? For example, if individuals are interested in entering some data for themselves, is the provider or payer PHR able to accept the data – an issue that could lead individuals to seek a separate PHR, ending up with multiple, fragmented PHRs when the goal is for PHR to be an integrating and connecting force.
- If patients see multiple providers and have a single PHR at one provider site, how will other providers feel about enabling electronic feed? This should be a moot point with an HIE.
- If the patient is no longer a patient, enrolled in the health plan, an employee, or have other relationship with the sponsor of the tethered PHR, how does their data transfer?
- What is the relationship of the sponsor to the data? While many sponsors state they do not have access to the data, others de-identify and aggregate the information for their business purposes.

Alternatively, the tethered PHR model, especially when associated with providers, closely aligns the patient with the provider. Care can be more proactive, such as when part of the PHR process is patient entry of data in advance of a visit (e.g., Instant Medical History – a utility found in a number of EHRs), connecting home monitoring devices (e.g., a physiological monitoring watch wirelessly connected to a transmission device), and the patient receiving health education. These are time saving features for both provider and patient. Providers may also place more trust in the integrity of the data when the PHR is under their control. Again, an HIE would further enable such alignment among all providers and other sponsors or participants in the HIE.

Standalone PHRs are those not integrated with any other system. In general, the strengths of one model are the weaknesses of the other. Perhaps the two biggest issues relate to data capture and data integrity, although providers may have such issues with any PHR model, including when tethered to another sponsor. Another issue associated with standalone PHR vendors is the dynamic marketplace. Many vendors come and go, some claim to be PHR vendors when only offering modest services, and some have grand plans and never get off the ground. One of the oldest forms of standalone "PHR" is the MedicAlert jewelry. One of the newest standalone PHR is Microsoft HealthVault, and Google has also announced a PHR.

# Platforms

- Many PHRs are web-based
- Some PHR vendors supply a license for software to run on a personal computer or portable device
- Some web-based PHRs enable generation of copies to portable devices or print outs, such as wallet cards
- Some vendors supply forms, instructional manuals



Examples

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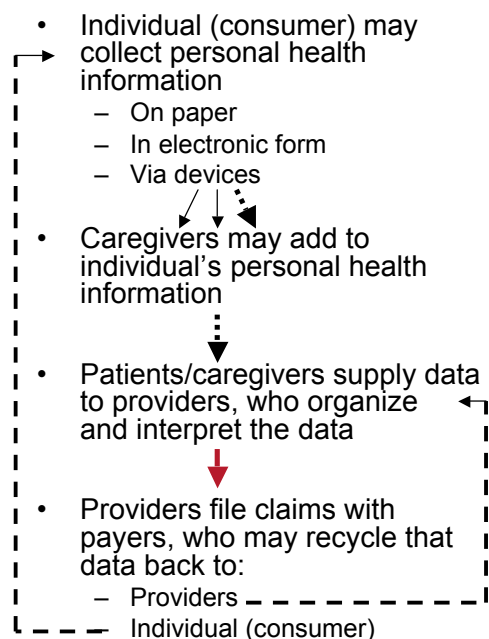
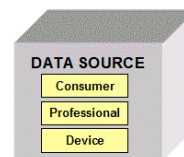
There are many platforms for PHRs. Many PHRs are web-based, but a savvy smart phone user may want to check that the web pages have been optimized for display. For older consumers, or even for caregivers of older individuals, it may be important for the web-page font to be easily sizeable, again a concern for optimal display.

Some PHRs are highly portable – on a CD, flash drive, or smart card. These can be convenient, but:

- Can they be universally read? A flash drive that runs on a USB port is quite universal; while smart cards and CDs may not be as universal as one might think. For example, even if a reader is supplied on the CD, a provider who uses a tablet at the point of care, as frequently desired for an EHR, generally would not have a CD reader. This would entail finding a desk top in an office to read the CD – a workflow issue that many providers may not want to undertake. Smart card readers may be even less universally available, especially for individuals themselves to use.
- Are they free from viruses and other malware? While virus protection should be installed on all systems in any provider setting, there can still be risk, especially for devices not recently connected to their network.
- Are individuals trained to safeguard their mobile PHR (or any form of PHR)? The universality of the device may well be its downfall if individuals do not password protect the device and guard it from loss. Well-publicized breaches of security have occurred as a result of tapes, disks, or hard drives that have fallen into the hands of someone with nefarious intent. Many of these have not been as secure as they could be. (See [www.cms.hhs.gov/SecurityStandard/Downloads/SecurityGuidanceforRemoteUseFinal122806.pdf](http://www.cms.hhs.gov/SecurityStandard/Downloads/SecurityGuidanceforRemoteUseFinal122806.pdf))

Paper in a variety of forms, from files folders to structured portfolios and wallet cards are available. While potentially not as secure as their electronic counterparts, they may be essential when information is needed in an emergency department that only has monitors and keyboards without a USB port or the individual is incapable of supplying sufficient information for web-based access (although many in emergency medicine say there is precious little time for any such detective work). Individuals may keep PHRs on PCs at home (or at the office – which could be a violation of employee property or, at a minimum, a potential privacy concern).

# Data Sources



## Data from Consumer

- Personal identification
- Next of kin and emergency contacts
- Provider names and contact information
- Health insurance information
- Living wills, advance directives, organ donor authorization
- Family history and hereditary conditions
- Correspondence with providers
- Dates of significant illnesses, surgeries

## Data from Providers, Payers

- Recent physical exam
- Opinions of specialists
- Important test results
- Eye and dental records
- Release of information, consent for surgery/procedures, research
- Current medications and dosages
- Immunization history
- Allergies and reactions

## Data from Devices, e.g.,

- Glucometers
- Blood pressure monitors
- Precision weight scales

## Timeliness and Accuracy?

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The nature of the data maintained in a PHR ranges from minimal to sophisticated. While the patient (and/or patient's caregiver) is largely the supplier of most data about themselves, many providers discount data recorded by patients when they would normally interview the patient and record it themselves. Some believe the process of filtering is useful; while others express concerns that the filtering may be one of the important reasons for patient entry of their own data.

There are many important elements to consider for data entered into a PHR, but two of critical importance are timeliness and accuracy – from both the individual and provider perspective. Some issues of timeliness relate to convenience – individuals are anxious for their lab results; for the provider lab results may not be available from the lab, have not been reviewed by the ordering provider, may only be preliminary, etc. Other issues of timeliness can make a significant difference in care. A lost test result can mean a repeat of the test that is not only costly and inconvenient but may delay treatment or result in a more conservative treatment than desirable.

Providers may question the accuracy of at least some data entered by some individuals or caregivers, although establishing a relationship in advance of receiving such data and verifying the data are professional responsibilities that should help assess the level of trust that seems appropriate for any given situation. Trust issues arise as both intentional and unintentional – with legitimate concerns about both “frequent fliers” and individuals who may not be able to manage data entry due to frailty, lack of keyboarding skills, poor health literacy, or a host of other issues where there is no intent to be inaccurate.

There are also concerns about the accuracy of data coming from claims data that may be recycled by payers or pharmacy benefits managers back to the PHR (or even the EHR). For example, it is well known that even the most accurate ICD and CPT coding still only describes a diagnosis or procedure at a very macro level. It is also known that ICD and CPT coding is not as accurate as it could be. There are also errors in pharmacy claims – often as a result of a transcription error by the pharmacy (which should be significantly reduced with e-prescribing).

# Additional Information/Services

## ADDITIONAL DATA

- Care management plans
- Patient-specific instructions (e.g., for wound care, medication administration) in multi-media, languages
- Culturally-sensitive, patient-specific education
- Chronic care monitoring (e.g., diabetic diary)
- Direct links to monitoring devices (e.g., physiologic monitoring)
- Eligibility for participation in a clinical trial or other research
- Diet, exercise, and other lifestyle information

## POTENTIAL PHR SERVICES

- Appointment scheduling and reminders
- Co-pay collection, eligibility verification, and consumer-direct health plan functions
- Secure messaging
- Graphing test results
- Integration of knowledge sources and guideline-based reminders for wellness, preventive care, and self care
- Drug-drug interaction checking, especially for over-the-counter drugs and supplements
- Healthcare quality and cost comparisons
- Consent directives to manage access and disclosures
- Audit logs
- Services, software wizards, and HIE utilities that make it simple for individuals to set up connections
- Reporting for post market pharmaceutical vigilance or public health surveillance

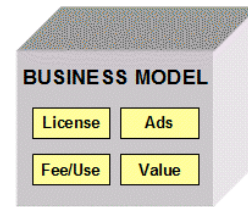
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The previous slide listed the data most commonly included in PHRs. Additional data that might be collected via PHRs is identified here. In addition to capture of data, there are a number of other services that may be supplied through a PHR – from those associated with administrative and financial functions, through care planning and management, to maintaining privacy and security, and social-minded services.

# Business Model



- PHR vendors usually rely on revenue from a combination of:
  - Advertisements
  - Licensing fees
  - Subscriptions
  - Fee for use/transaction fees
- PHR sponsors, however, often supply these products to their patients, members, employees, participants, etc. for “value”
  - Process efficiency
  - Loyalty and marketing
  - Messaging
  - Behavior and outcomes

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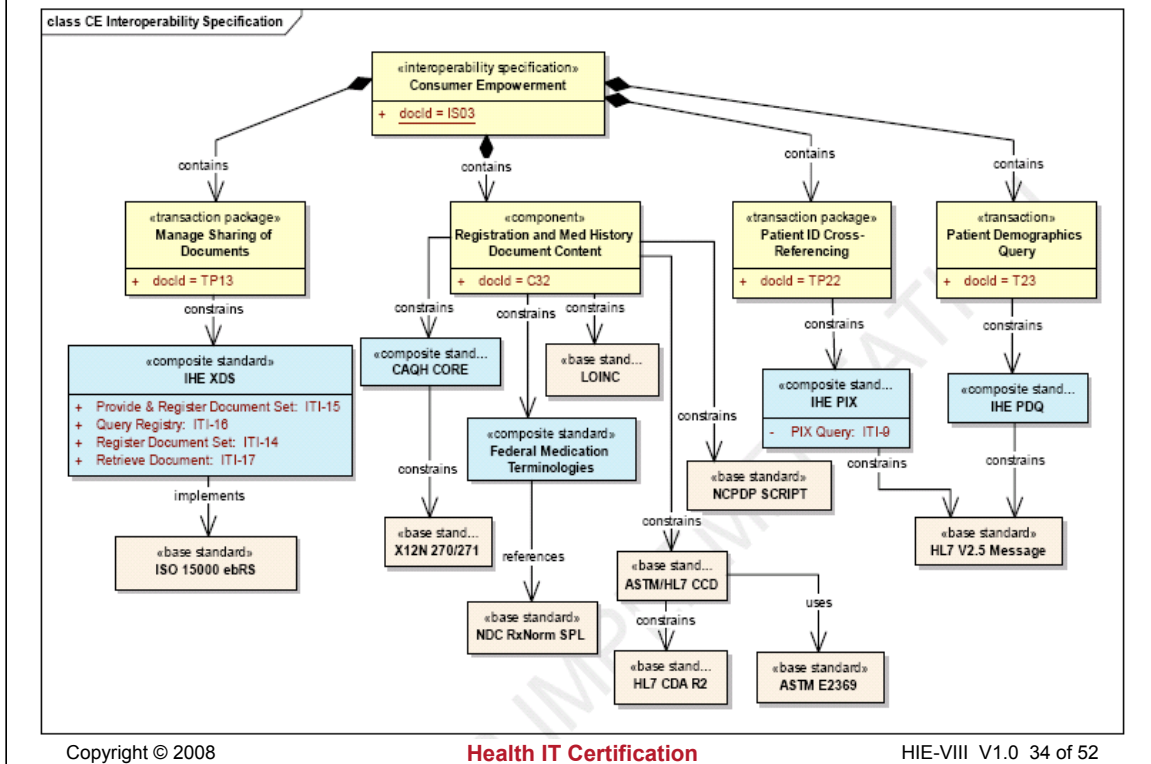
HIE-VIII V1.0 33 of 52

The final dimension to be discussed for PHRs is their business model. While there are some “free” PHR services on the web, these are likely to be paid for through some form of sponsorship, such as advertisement. An advertisement-free PHR probably needs to come through direct payment, such as licensing the software or subscribing to a service – irrespective of whether an individual acquires use of the PHR or a sponsor does so on behalf of a group of individuals. Individuals or sponsors may also be charged fee for use or transaction fees – much like telephone companies, there is basic service and then per phone call.

Sponsors who supply PHRs “free” to their patients, members, employees, etc. generally do so because of the inherent value they perceive they will derive. Providers may decide to support a PHR because patient entry of data reduces the data entry burden for the provider. They may believe it builds loyalty in their patients, or believe that they result in better care and outcomes and want that for the value it contributes to their contracting power (as well as personal satisfaction for quality of services delivered). Payers (including the federal government as the largest payer) may also derive some process efficiencies, but also want to influence outcomes to lower their costs and increase profitability. Employers may want to send a clear message to employees that a healthy workforce is a productive workforce and one that strengthens the financial stability of the company and the overall economy. While it may not be important for some consumers to understand the value proposition in a PHR, it is certainly front and center for many sponsors.



# HITSP C.E. Interoperability Specification



To achieve the PHR in any of its dimensions, standards for data content, format, and transmission are essential. With the exception of a PHR maintained solely by an individual with data generated only by the individual (or caregiver), a PHR by its nature is a means to connect and supply information across the continuum of care. The more standard the data content, format, and transmission processes, the more meaningful is the PHR.

In addressing the AHIC use case for consumer empowerment, HITSP developed the consumer empowerment interoperability specification (C.E. I.S.). (Refer to CPHIE Course VI for a primer on reading UML use cases in general and the structure of the HITSP interoperability specifications in particular.) The C.E. I.S. contains the ability to manage sharing of documents, maintain registration and medical history document content, cross reference patient identification, and query patient demographics. Although there are other functions that PHRs may perform, these are basic and drawn from the minimum AHIC use case requirements. The standards that constrain these four major content elements are described on the next slide.

# Standards Linked to HITSP Constructs

| Standard   | Description and Use   |
|--|---|
| ASC X12N 004010  | HIPAA transactions; informative mapping to CCD  |
| ASTM E1633-02; E2369-05 CCR  | Lexicon for coded values in EHR; CCR maps to CCD  |
| CDC Race & Ethnicity Code Sets   | Referenced in CCD   |
| CAQH/CORE Operating Rules  | Business rules for eligibility inquiry & response transactions; maps to CCD             |
| CLIA of 1988   | Quality standards & basis for CMS regulations for labs                                  |
| Federal Medication Terminologies   | RxNorm, UNII, NCI, NDF-RT   |
| Healthcare Provider Taxonomy   | Code set to identify specialty of individuals   |
| HL7 EHR-S FM; V2.5 & V3.0; CDA; CCD                                      | Functional Model; messaging standards and code sets; XML-based document markup standard |
| Integrating the Healthcare Enterprise (IHE)                              | Integration profiles of established standards   |
| IHTSDO SNOMED CT®  | Core content and framework to manage clinical content                                   |
| Logical Observation Identifiers Names and Codes (LOINC®)                 | Database of identifiers for lab and other clinical observations                         |
| National Council for Prescription Drug Programs (NCPDP) SCRIPT           | Standard for real time electronic transfer of prescription data                         |
| Rev. to Standards for Classification of Federal Data on Race & Ethnicity | Minimum standard for all Federal-reporting of race & ethnicity                          |
| UCUM   | Code system for units of measure  |

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Standards linked to the HITSP constructs in the Consumer Empowerment Interoperability Specification are identified here. Many provide informative mapping to the HL7 Continuity of Care Document (discussed on subsequent slides). Standards not described elsewhere in this program include:

- ANSI Accredited Standards Committee (ASC) X12 Insurance Subcommittee (X12N), version 004010, standards are those used for claims, eligibility verification, etc. under HIPAA. They are published by the Data Interchange Standards Association (DISA) at [www.x12.org](http://www.x12.org)). Implementation guides are published by Washington Publishing Company ([www.wpc-edi.com](http://www.wpc-edi.com)).
- Centers for Disease Control and Prevention (CDC) Race and Ethnicity Code Set is based on current federal standards defined by the U.S. Office of Management and Budget ([www.cdc.gov/nedss/DataModels](http://www.cdc.gov/nedss/DataModels))
- Council for Affordable Quality Health Care (CAQH) Committee on Operating Rules for Information. Exchange (CORE) Operating Rules provide agreed-upon business rules for using and processing eligibility inquiry and response transactions between providers and health plans ([www.caqh.org](http://www.caqh.org)).
- Clinical Laboratory Improvement Amendments (CLIA) of 1988 establishes quality standards for all laboratory testing to ensure the accuracy, reliability, and timeliness of patient test results regardless of where the test is performed. CMS regulates all laboratory testing (except research) performed on humans in the U.S. based on CLIA ([www.fda.gov](http://www.fda.gov) and [www.cms.hhs.gov](http://www.cms.hhs.gov)). CLIA rules in each state provide requirements for review of results by the ordering provider prior to their being able to be released to others.
- Federal Medication Terminologies represent a collaboration between the Food and Drug Administration, National Library of Medicine, Veterans Health Administration, National Cancer Institute, and Agency for Healthcare Research and Quality related to medications, including medication proprietary and nonproprietary names, clinical drug code (RxNorm); ingredient names and Unique Ingredient Identifiers (UNII); routs of administration, dosage forms, and units of presentation from the NCI Thesaurus (NCIt); and certain pharmacological drug classes from the National Drug File Reference Terminology (NDF-RT).
- Unified Code for Units of Measure (UCUM) is a code system intended to include all units of measures being contemporarily used in international science, engineering, and business. The purpose is to facilitate unambiguous electronic communication of quantities together with their units ([www.aurora.regenstrief.org](http://www.aurora.regenstrief.org)).



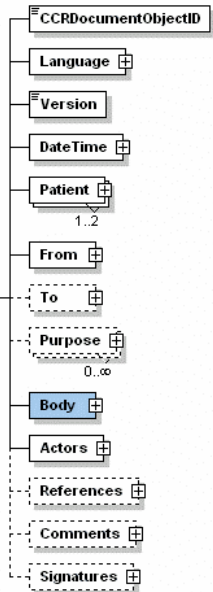
# CCR + CDA



E 2369-05  
Standard  
Specification for  
Continuity of Care  
Record,

ContinuityOfCareRecord

A2. Implementation  
Guide, contains  
instructions for  
generating a  
standards-  
compliant CCR  
XML document



```

+ <custodian>
- <recordTarget>
- <patient>
  <id extension="12345" root="2.16.840.1.113883.3.933" />
  <patientPatient>
  - <name>
    <given>Henry</given>
    <family>Levin</family>
    <suffix>the 7th</suffix>
  </name>
  <administrativeGenderCode code="M" codeSystem="2.16.840.1.113883.5.1" />
  <birthTime value="19320924" />
  </patientPatient>
+ <providerOrganization>
</providerOrganization>
</patient>
+ <recordTarget>
+ <relatedDocument typeCode=
+ <componentOf>
- <!--

.....
CDA Body
.....
->
- <component>
- <structuredBody>
- <!--

.....
History of Present I
.....
->
- <component>
- <section>
  <code code="10164-2" codeSystem="2.16.840.1.113883.6.1" codeSystemName="LOINC" />
  <title>History of Present Illness</title>
  <text>
  - <content styleCode="Bold">

```

HL7 V3.0 Clinical Document Architecture (CDA): XML-based document markup standard that specifies structure and semantics for clinical document exchange

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An important set of standards for PHRs and their use within an HIE includes the harmonization of the ASTM Continuity of Care Record (CCR) standard with the HL7 Clinical Document Architecture (CDA). As described earlier, the CCR data content specification is widely used as the standard for what data should be included not only in the exchange of referral information among providers, which was its original intent, but for PHRs as well. HL7 CDA is also broader than PHRs, designed originally as a document markup standard for any use of an electronic document management system (EDMS), widely used in hospitals to achieve a paperless environment, and often used in physician offices for chart conversion (i.e., scanning active patients' paper charts into an EHR for ease of retrieval). Although the data content of a CCR could be transmitted via a standard HL7 message, scanning of documents (or electronically feeding digital dictation, speech dictation, transcription, email, efax, or other digital documents) provides a "gentle on-ramp" to information exchange that is both EHR-compatible, yet not requiring an EHR. The combination of CCR and CDA provides an excellent tool for PHRs (as illustrated on the next slide).

# = CCD (Rendered in PDF)

## Patient Demographics

| Name               | Date of Birth                        | Gender | Identification Numbers              | Address / Phone   |
|--------------------|--------------------------------------|--------|-------------------------------------|---|
| Barbara L Campbell | Date of Birth: 7/26/1972 12:00:00 AM | female | Social Security Number: 652-07-4756 | Home:<br>327 Farm Road<br>Round Rock, TX<br>Home: (320)804- |

## Alerts

| Type    | Date                             | Code | Description | Reaction   | Source                        |
|---------|----------------------------------|------|-------------|------------|-------------------------------|
| Allergy | Initial Occurrence: Jan 20, 2006 |      |             | - Moderate | <a href="#">Levi A Wright</a> |
| Allergy | Initial Occurrence: Jan 20, 2006 |      |             | - Severe   | <a href="#">Levi A Wright</a> |
| Allergy | Initial Occurrence: Jan 20, 2006 |      |             | - Mild     | <a href="#">Levi A Wright</a> |
| Allergy | Initial Occurrence: Jan 20, 2006 |      |             | - Moderate | <a href="#">Levi A Wright</a> |

## Problems

| Type      | Date                | Code             | Description                        | Status  | Source                          |
|-----------|---------------------|------------------|------------------------------------|---------|---------------------------------|
| Diagnosis | Onset: Apr 11, 2003 | 368.8 (ICD9-CM)  | Other specified visual disturbance | Chronic | <a href="#">Bryce FF Miller</a> |
| Diagnosis | Onset: Jan 23, 2003 | 461.0 (ICD9-CM)  | Acute sinusitis, maxillary         | Active  | <a href="#">Bryce FF Miller</a> |
| Diagnosis | Onset: Sep 03, 2002 | 599.0 (ICD9-CM)  | UTI                                | Active  | <a href="#">Jackie Enders</a>   |
| Diagnosis | Onset: Sep 03, 2002 | V72.3 (ICD9-CM)  | Well woman exam                    | Active  | <a href="#">Jackie Enders</a>   |
| Diagnosis |                     | 780.2 (ICD9-CM)  | Fainting spell                     | Active  | <a href="#">Jackie Enders</a>   |
| Diagnosis |                     | 462 (ICD9-CM)    | Pharyngitis, acute                 | Active  | <a href="#">Jackie Enders</a>   |
| Diagnosis |                     | 477.0 (ICD9-CM)  | Allergies                          | Active  | <a href="#">Jackie Enders</a>   |
| Diagnosis |                     | 461.1 (ICD9-CM)  | Sinusitis, frontal                 | Active  | <a href="#">Jill Byrd</a>       |
| Diagnosis |                     | 691.8 (ICD9-CM)  | Atopic dermatitis                  | Active  | <a href="#">Jill Byrd</a>       |
| Diagnosis |                     | 813.05 (ICD9-CM) | Closed fracture of head of radius  | Active  | <a href="#">Bryce FF Miller</a> |

## Medications

| Medication                                      | Date                                | Status | Form   | Strength | Quantity              | SIG  | Indications | Instruction                | Refills | Source                        |
|---|-------------------------------------|--------|--------|----------|-----------------------|------|-------------|----------------------------|---------|-------------------------------|
| Ethinyl Estradiol/Levonorgestrel (Triphasil 28) | Medication Start Date: Sep 03, 2002 | Active | Tablet |          | 1 28 tablet dial pack | Oral |             | as directed.; as directed. |         | <a href="#">Jackie Enders</a> |
| Ethinyl Estradiol/Levonorgestrel (Triphasil 28) | Medication Start Date: Sep 03, 2002 | Active | Tablet |          | 1 28 tablet dial pack | Oral |             | as directed.; as directed. |         | <a href="#">Jackie Enders</a> |

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The result of the harmonized ASTM CCR and HL7 CDA is called the Continuity of Care Document. Although it may be rendered in XML (as illustrated on the previous slide), it may also be rendered as a PDF file, as illustrated here. A key element of the CCD that makes it a desirable structure for PHRs is not only the standard data content but that all data are sourced to their original author. What may not be visible here is that when data are sourced, access controls on the data enable viewing but not alteration. The potential lack of data integrity in a PHR has been a major concern of providers – and frequently the solution is not well-known or understood. It is also the reason that many PHRs are constructed so that the consumer can supply information, side-by-side, with other-sourced data. For example, if the source of a prescription is a specific provider or a pharmacy benefits manager (PBM) reporting a drug claim, a consumer may wish to annotate that they are taking only half the dose, or stopped taking it halfway through the prescribed treatment regimen, or experiencing an adverse reaction. This provides valuable information associated with the drug, but does not alter the fact that the drug was prescribed by a certain provider and filled by a pharmacy.

# **Personal Health Records**

## **Part 4. Policies and Practices for PHRs in HIEs**

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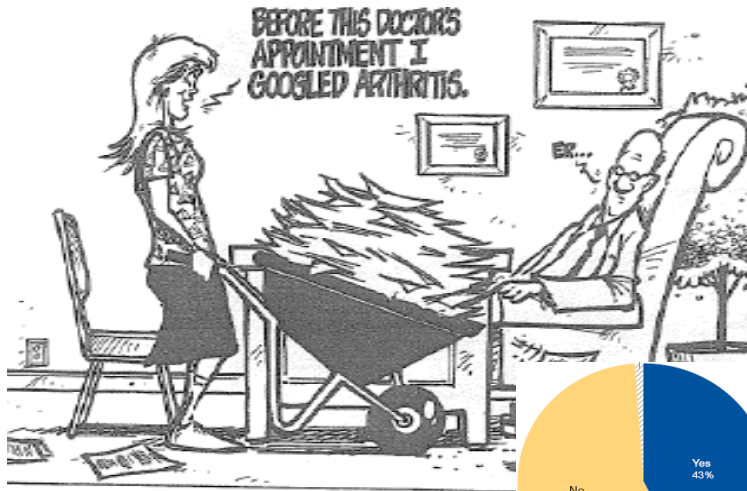
So, with the consumer movement upon health care and PHR attributes and standards becoming more well-known and available, it is important to consider policies and practices for use of PHRs in HIEs.

## Content Part 4.

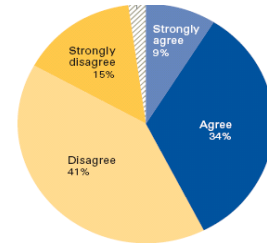
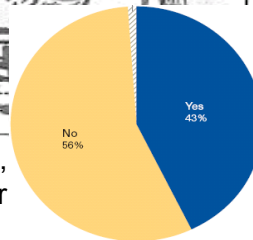
- Provider Concerns
- Three PHRs: Challenges and Recommendations
- Clinical Messaging
- PHR Interest and Use by Consumers
- PHR in HIE
- Managing Data Quality for PHR in HIE

As with any new construct that portends great benefits, PHRs have also raised concerns and provide organizations sponsoring them with challenges. Part 4 of this Course describes the current state of affairs with respect to concerns and challenges, and describes a number of solutions that thought leaders and early adopters have begun to embrace. Hopefully this provides direction to HIEs as they consider how they may use PHR in their development.

# Is This Your\* Greatest Nightmare?



After obtaining health information online, consumers discuss it with their doctor



Consumers say they depend on the Internet to help them make personal health decisions

Don't know, Don't remember

## \*Provider's

Source: Custom Study for California HealthCare Foundation, Manhattan Research, 2006/2007, March 2008

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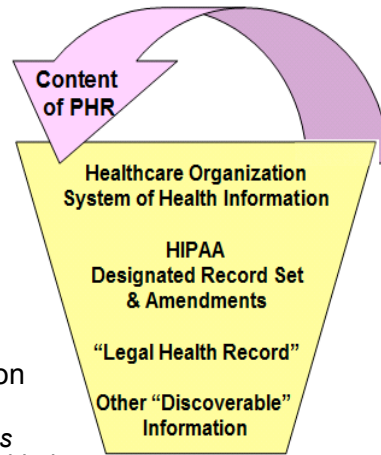
Perhaps the greatest fear of providers with respect to PHRs is illustrated by this cartoon: that they will be barraged with mounds of disorganized paper (or its electronic equivalent). Hopefully, this notion has been dispelled by the description of what is feasible with a PHR that follows the HL7 CCD structure. Hopefully also, providers come to recognize that informed consumers are their best partners in making clinical decisions. When an office visit may last only 7 or 8 minutes, individuals need to be as savvy about their health care as their providers.

It is clear that consumers are increasingly using the Internet to help them make personal health decisions. Witness a simple event – one that has surely occurs all the time: a patient experiences a simple ear infection, goes to an ENT specialist, fails to mention (or is not asked about) gastrointestinal problems and depression, and is prescribed a steroid. An adverse reaction results in major discomfort and dehydration, and finally a visit to the emergency department, where it is recognized that the steroid is contraindicated for patients with gastric ulcers and depression. A combination of a muscle relaxer, pain medication, antacid, and acid blockers are necessitated. Upon returning home and doing a quick check online, it becomes brazenly clear that consumer empowerment was needed in the first place.

And these concepts are not new. As early as 1997, Tom Ferguson, MD, observed “The primary practitioner in our health care system should be the informed, empowered online layperson – and the main role of health professionals is as coaches, teachers, supporters, and cheerleaders for system-wide, computer-supported, high quality, low-cost self-managed care.” (*Health Data Management*, November 1997)

# Addressing Provider Concerns

- Some providers believe that patient accessibility to their health information adversely affects the quality of the record, causing providers to make cautious, guarded entries, and to omit information
  - *Evidence suggests access to health records and health information better engages patients in managing their health and health care*
- Some providers believe patient provision of PHR content
  - Increases liability for content not reviewed or addressed during an episode of care
    - *Suggest patient use PHR as personal resource during visit rather than supplying all to office*
    - *Utilize structured data entry to guide input*
  - There is no reimbursement for review
    - *There may be productivity gains from patient data entry into templates*
  - Increases risk of security incidents
    - *Utilize secure web portal or HIE*
  - Increases risk of alteration and requires validation and version control
    - *Ensure all data are sourced, and appropriate access controls and audit logs, reviewed regularly, are provided*



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There are strategies to deploy when faced with the inevitable reams of output or a flash drive with a gigantic spreadsheet created by the patient who wants the provider to take all of the information, digest it, and treat every ill immediately (or so it may seem to the recipient provider). A first step is to establish some thoughtful policies – recognizing the importance of the information to both the patient and provider. Specific fears concerning liability for information that may be embedded in the PHR can be allayed by suggesting the patient use the PHR as a personal resource, not giving it to the provider. If the provider uses an EHR that includes a tethered PHR, the risk of more than you can manage is significantly reduced. The more structured guidance for what to put into a PHR tethered to the EHR also means less time to review, it is feasible for new information to be flagged to the EHR, and certainly, some of the data entered in to the PHR can be moved to the EHR and reduce time for provider data entry. Again, a tethered PHR operated via a secure web portal reduces risk of introducing viruses or just the inconvenience of having to manage with a different software driver. If the patient uses a standalone PHR, an appropriate policy may simply be to request the patient to enable access by the provider – which supports a secure portal as well.

Of course, a PHR supported through an HIE overcomes many of the issues and serves as a tethered model, but tethered to a much broader group of providers the increase the sharing capability.

## Three PHRs: Challenges and Recommendations

- Should sensitive diagnoses be shared?
  - Yes, even sharing psychiatric diagnoses encourage helpful discussion between providers and patients
  - With appropriate security measures (see next slide); and where state laws do not pose legal barriers
- Should entire medication list be shared?
  - Yes, enabling patients to reconcile their own medications is a powerful way for providers to meet The Joint Commission requirements
  - Provider-based and patient-maintained lists are maintained side-by-side, showing origin of documentation and updates
- Should all lab test results be shared?
  - Variations in workflow due to state law restrictions
    - Set timeliness expectations for physician review, backed up with automated release after defined period of time
    - Multiple configurable, clinician-specific preferences were ultimately rejected in favor of single least restrictive clinician rule

Halamka, JD, KD  
Mandl, PC Tang,  
“Early  
Experiences  
with Personal  
Health  
Records,” *JAMIA*,  
Jan/Feb 2008

- MyChart at Palo Alto Medical Foundation, California
- PatientSite at Beth Israel Deaconess medical Center, Massachusetts
- Indivo at Children’s Hospital Boston, Massachusetts

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Even more specific issues, however, are challenging once you decide to provide patients access to information in an EHR, support a PHR, or participate in an HIE that utilizes a PHR in some form. Three early adopters share their challenges and strategies to overcome them in an article in the *Journal of the American Medical Informatics Association*. Based on three separate products used in two different states, the authors ask questions that are certainly on the minds of many. These questions and their responses are apropos whether the PHR is tethered, standalone, or part of an HIE. In general, the authors seemed to have reached very similar conclusions, or at least desires with resultant variations driven more by state law than personal preference. The authors also seem to suggest that they have had to drive some stakes into the ground – for example, receiving lab results as quickly as possible is a key interest to consumers. They don’t know about CLIA and its potential restrictions. So the provider organizations taking action that requires timely review of lab results is a key element of their success.

## Three PHRs, Continued

- Should clinical notes be shared?
  - Access supplied upon request:
    - Level of explanation required to help patient understand impedes sharing and most PHRs do not include for this reason.
    - Patient-friendly summaries and piloting of note sharing is occurring
- Should patients be authenticated to access PHR?
  - Yes, via username and password granted by institution, to ensure positive patient identification, maintain medical integrity of the record, and assure privacy
- Should minors have access to PHR; should patients be able to share access via proxies?
  - Variations in practice due to state law, but provision to primary guardian only, parents and patients with potential restrictions, and provision to patients over 18 with caretakers if desired

### Online Security Measures

- HTTPS encrypted connection
- Designate all web pages as “do not cache”
- Set browser to “page already expired” to prevent any trace of data left in browser or on the computer that accessed it

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In addition to the challenges which these three organizations have grappled with and addressed - at least for now, they also anticipated some new challenges:

- Those institutions with institution-based (tethered) PHRs believe that their patients may want a single PHR that works with all their sites of care. (Note: Indivo Personally Controlled Health Record (PCHR) at Children’s Hospital Boston is an open-source application platform developed in partnership with the Dossia Consortium.) They suspect their patients will want to view consolidated data and add their own entries such as over-the-counter medications, quantitative measurements from monitoring devices, and qualitative observations such as self report of symptoms or notes. They anticipate moving to a service oriented architecture that permits multiple applications to retrieve their institutional data with patient control and consent.
- Currently none of the institutions support electronic data input from outside institutions. They report that their patients want coordinated care among their providers. They note that tracking a comprehensive medication list across all sites of care should reduce errors, improve quality, and reduce the frustration of all stakeholders who seek this information repeatedly from patients. They envision a PHR that may receive various electronic feeds, support import of a continuity of care document (CCD), and scanning of paper documents provided by the patient.
- The organizations also recognized that their patients may want to integrate knowledge sources on the Internet with their PHRs, connect to communities of others with similar diseases, and participate in clinical trials, post-market pharmaceutical vigilance, or public health surveillance, especially through de-identified data. As they move forward with their PHR initiatives, these will be new avenues for them to address.

# Clinical Messaging

American Medical Association  
Physicians dedicated to the health of America



Home | Member Center | AMA Agenda | Newsroom | Professional Resources | Doctor Finder | Med School

Member Center  
Become a member

**Guidelines for Physician-Patient Electronic Communications**

<http://www.ama-assn.org/ama/pub/category/2386.html>

- Volume of messages no more than phone calls, generally able to be handled in less time
- Jury is out on whether e-visits are cutting into better-reimbursed office visits or simply replacing non-reimbursed calls
- Some health plans, employers, and patients themselves are paying \$20-\$30 per e-visit (**CPT 0074T**)
- Important to establish guidelines for e-mail communications of all kinds, and specifically what may constitute an e-visit
- AMA, ACP, several malpractice insurance carriers, and early adopters provide guidance
- Another, less electronic, alternative is a telephone appointment

## Signature Line:

*/s/ Sam Ple, MD*  
Samuel Ple, MD  
Dermatology  
1 Main Street  
City, State, Zip  
Phone: 999-555-1234  
Email: sam.ple@MD.com

**Call 911 in emergency or go to the ER!**

Call office if urgent  
*Please follow security guidelines*

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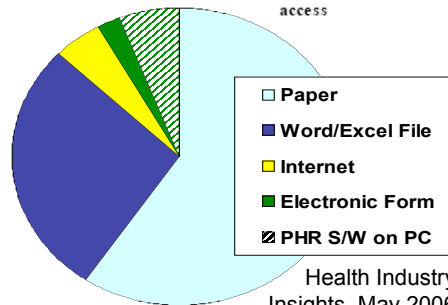
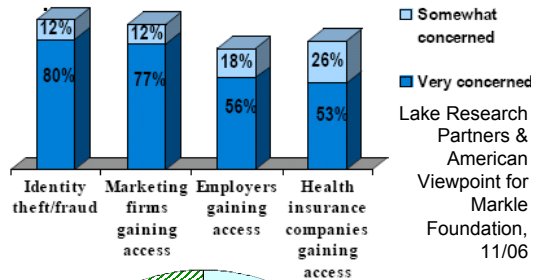
One very common function that many providers are asked to supply, and which an increasing number are engaging in, is clinical messaging. Clinical messaging may occur among providers, but also with patients. It is the secure exchange of individually identifiable health information to communicate information quickly and to engage in conversation about a current health issue. Clinical messaging can be a part of a PHR, but may also be a pre-cursor to a PHR.

Clinical messaging, also of concern to busy health professionals, has been found to be no more time consuming than managing phone calls, and in many cases in less time. Some payers are starting to reimburse for legitimate e-visits, for which there is a CPT code available. As you approach clinical messaging, whether within a given practice setting or across an HIE, care should be taken to develop policies and procedures that set appropriate boundaries for what constitutes appropriate use of clinical messaging.

# PHRs – Much Interest, Less Use, Continued Concerns by Consumers

- 42% of adults keep personal or family health records
- 84% think it would be a good idea
- 13% who have a PHR have electronic
- More women (45%) than men (38%), and the elderly (58%) keep PHR
- Reasons for interest in PHR:
  - Ability to provide physicians information (78%)
  - Ability to recall care (78%)
  - Access in emergency (77%)
  - Proper use of drugs (54%)
- Concerns about:
  - Threat to privacy (68%)
  - Security (66%)
  - Errors (37%)
  - No access in emergency (37%)
  - Not current (33%)

If a network existed to provide people with access to their personal health information online, how concerned would you be about . .



HarrisInteractive 2004

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Health Industry Insights, May 2006

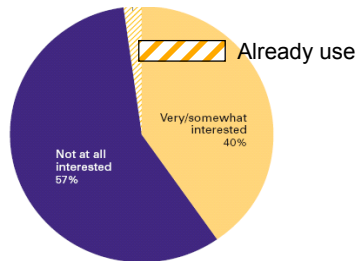
HIE-VIII V1.0 45 of 52

Providers clearly have legitimate concerns and many providers have found appropriate strategies to effectively enter the information age, and even the connected age!

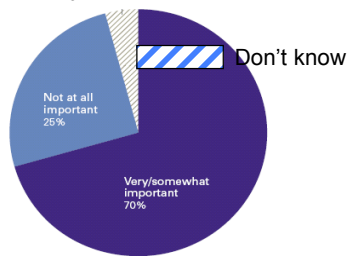
But the question could well be asked also, how much interest is there actually from consumers? Harris Interactive and other pollsters have been attempting to capture the pulse of healthcare consumerism with respect to information technology use for some time. This next set of slides provides data from 2004 through 2008 from a variety of sources. Interestingly, Harris Interactive observes not a lot has changed over that period of time. There appears to be very strong interest for PHRs, but less actual use, at least in use of Internet-based or even special software for PHR; and there are real concerns about privacy and security. Certain market segments and certain uses and users are of special concern to individuals. It is also interesting to note that the elderly are among the most interested – whether they use the technology or have someone else assist them.

# Consumer Readiness

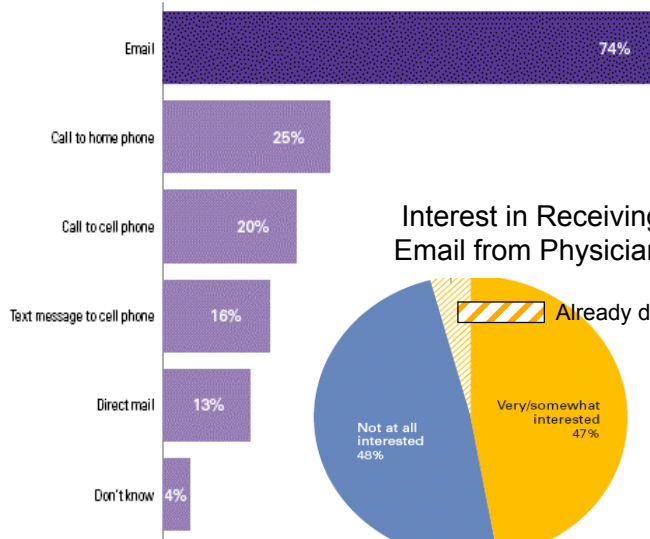
Interest in Accessing PHRs Online



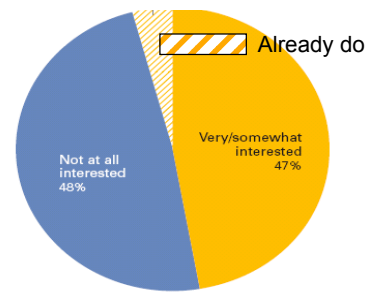
Importance of Technology in Physician Office



Interest in Receiving Prescription Refill Reminders



Interest in Receiving Email from Physician



Source: Custom Study for California HealthCare Foundation, Manhattan Research, 2006/2007, March 2008

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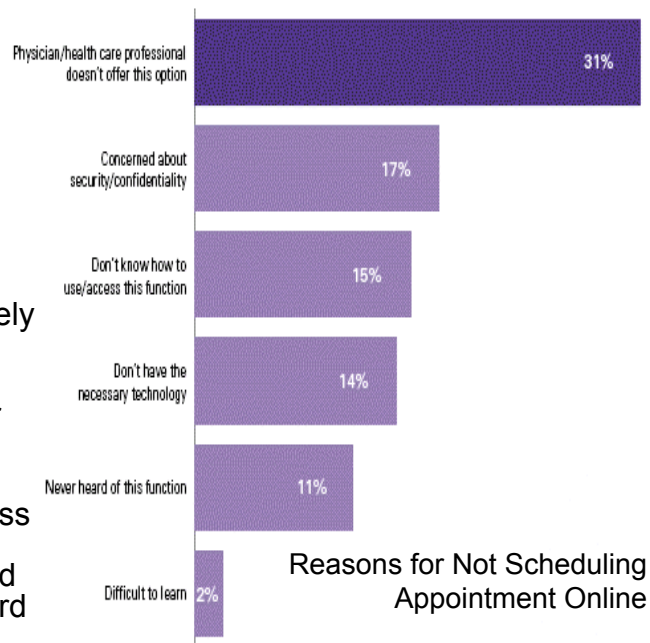
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It is also interesting to observe some disconnects as individuals respond to these surveys. For example, 57% of respondents to a survey conducted in 2006/2007 and reported in 2008 indicate no interest at all in accessing PHRs online, yet 70% of the same respondents believe it is somewhat or very important for their physician to use an EHR. Respondents in this survey indicate that there is very strong interest in receiving email reminders of the need for prescription refill; yet 48% are not at all interested in receiving email from their physicians, with about 5% exchanging email today and another 47% interested in receiving email.

# Need for Education

- Health education in general; “teachable moments” for adults
- Development of trust
  - Providers must encourage patients to enter information accurately and to trust information appropriately
  - Consumers must trust that providers will only use the information for the individual’s benefit
- Objective evidence of efficiency and effectiveness may be required before consumers, providers, and regulators will move toward the goal of PHR adoption



Source: Custom Study for California HealthCare Foundation, Manhattan Research, 2006/2007, March 2008

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Other data from the same survey reveal that many consumers either do not know much about the potential for use of information technology in healthcare, or find their providers do not offer such technology. Of course, as EHR adoption by providers in ambulatory settings still at about 17% - 23%, it is not surprising that 31% of the respondents would reply in this manner. However, of potentially even more concern is that fully 32% of respondents report not knowing how to use the technology, not having technology to support use, having never heard of (the ability to schedule an appointment online), or finding it difficult to learn to use.

Many of the thought leaders have identified consumer education – in many aspects of health care – a critical and unmet need. Not only do consumers need to be more health literate, but many – even who may use computers on the job for certain limited functions – may need to learn how to navigate the Internet and potentially be savvy enough to learn how to use each of their provider’s portals, clinical messaging systems, or PHRs from different sponsors. The matter of trust – by both providers and consumers – was addressed in the CPHIE VII Course on Data Stewardship. It was also a common theme in the development of goals and governance for HIE, even among participating providers in an HIE, let alone with other stakeholders and consumers (CPHIE V: Goals and Governance).

# 10 Questions Consumers Should Ask

1. Will this PHR enable me to record all the health information I want?
2. Will information automatically be added to my PHR from other sources?
  - What information will be added? How will it be added? Is transfer auditable?
  - Is there opportunity to delete, correct, or add information? How? Is there an audit log?
3. Does PHR host or sponsor have any ownership rights to the information in the PHR?
4. Can the PHR host or sponsor sell the information to anyone for any reason?
  - If so, how can I ensure my privacy is protected?
  - Can I specify that my information not be sold?
5. Will my information be used for employment or insurance coverage decisions?
6. Who has access to information in my PHR?
  - Can I control who (provider, insurer, employer, caregiver, family member) has access to what information (e.g., demographics/insurance, medical, behavioral) and under what circumstances (e.g., specific healthcare encounter, emergency only, other)?
  - Is there an audit log of who has accessed my PHR?
7. If I no longer am employed, insured, or a patient of the host/sponsor, can I still continue to use the PHR?
8. How do I get my data if host/sponsor goes out of business? How can I transfer my PHR information to another PHR sponsor?
9. Will there be any cost for me associated with use of this PHR? Upfront, ongoing maintenance, per access, other?
10. Do you apply targeted advertisement to my PHR? If so, is there a way use my PHR without this advertisement? How am I assured that advertisers do not get access to my health information?

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As previously identified, the American Health Information Management Association (AHIMA) provides considerable support to individuals interested in using a PHR. They host a website, [www.myPHR.com](http://www.myPHR.com), to help individuals navigate the world of PHR. They suggest that consumers ask key questions of the host or sponsor of any PHR they are considering. This set of questions was compiled, in part, from their work. It is recommended that individuals get these responses and other information in writing before agreeing to subscribe to or participate in any PHR.

However, this set of questions can also be turned around into a checklist for any sponsor to consider. Even appreciating why the question may be asked by a consumer is an important step in developing a trusting relationship for any PHR in any environment.

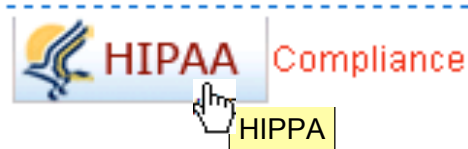
## “Cyberseals” of Approval (and Buyer Beware!)

- Online Privacy and Security Policy
- Terms and Conditions of Use
- Notice of Privacy Practices
- Advertising and Sponsorship Policy
- Certificate of security
- Certificate of compliance with other codes of health-related business



# Examples

- Federal government does NOT certify HIPAA compliance
- This linked to HHS/OCR, despite spelling error



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Many Internet-savvy consumers have come to look for various “cyberseals” of approval that the website they are accessing is secure (e.g., VeriSign, CyberTrust, TRUSTe, GoDaddy.com; or Hacker Safe). Users of health educational sites may recognize the HON seal as designating that the information is reliable (Health on the Net is an international organization that accredits health educational sites). Each of these seals provide a hyperlink to a website that confirms the reliability of the seal.

In addition to these common seals, Web surfers may be familiar with sites maintaining a privacy policy – the misuse of which would fall under the Federal Trade Commission regulatory power for assuring fair advertising practices. Other policies and statements that web sites are adding include terms and conditions of use, advertising and sponsorship policies, and other codes of good business practices. Outside of health care, that may be a seal from the Better Business Bureau or Good Housekeeping – which now has a web site certification program. Several accreditation programs have recently been developed to assure consumers (some potentially only in the business-to-business environment) of legitimate healthcare business practices, such as EHNAC, HCCO, and URAC, as well as the long standing accreditation of The Joint Commission.

Looking for such seals, policy statements, and terms of use can be very helpful, but must be followed up with checking their legitimacy. Not all seals represent quite what they imply. On surfing the ‘Net recently a “HIPAA Compliance” seal was found. On getting ready to click the hyperlink – which revealed a misspelling of the acronym, it was found that the link went to the HHS Office for Civil Rights (OCR) web site – an informational web site, not a certification or accreditation of compliance. Furthermore, consumers and even some vendors supplying the healthcare industry are often unaware that it is only covered entities defined in the HIPAA legislation (health plans, healthcare clearinghouses, and certain providers) who can be compliant with the HIPAA regulations; and certainly there is no official, federal government compliance seal, certification, or accreditation. Many new vendors or vendors new to the healthcare industry are entering the marketplace to support HIEs. In many cases, they draw their experience from integrating systems in other industries that can be very valuable. Stakeholders in the HIE, however, must recognize when their vendors need help in understanding this new market for themselves.



## Managing Data Quality for PHR in HIE

- While an overarching national architecture with standards for clinical data content transmission, terminology, and security would ensure interoperability; today, HIEs should adopt recommended and emerging standards, while advocating for a full suite and required conformance for interoperating among HIEs
- HITSP C.E. Interoperability Specification and others have identified a number of standards gaps:

### STANDARD VOCABULARY

- Consumer-oriented terminology for provider type role
- No recognized standard or vocabulary for explicitly expressing dose calculation
- No vocabulary for types of advance directives, currency, and non-repudiation
- No standard vocabulary for consumer-friendly problem list, medication list, and laboratory results. Also need heightened accuracy of such data from claims

### PRIVACY & SECURITY

- No standard methodology for consumers to request modifications and corrections to registration, medication, and other data
- HL7 is balloting a “permissions catalogue”
- Need two-tiered access control
- No standard content or format for audit logs or disclosure logs
- Harmonization among state laws for use and disclosure

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A final factor relating to PHRs is the adoption of standards, not only for the interoperability that enables exchange of data within an HIE, but for effective communication – enabling the message to impart the qualities of a conversation. There is no consumer-oriented terminology for much of health information. Much has been made of the need for consumers to provide consent for use or disclosure of their health information – but there are no standards for consent directives, there no standard classes of data or categories of use (which would fully enable the HIPAA Privacy Rule minimum necessary standard), let alone education to describe the benefits and risks of any given directive.

As a bit of editorial, it can be observed that HIEs face many risks today. There is very strong interest, with very little sustaining resources. The concept is espoused without the recognition of the need to address the underlying competitive environment and garnering trust. Goals are lofty with minimal formality to governance structures. Standards exist, but full conformance is still elusive. Service oriented architecture exists, with only the beginning of its adoption due to the large legacy infrastructure. Likewise, PHRs are an important element of HIE. They may be sustainable on their own, but they would surely thrive by far better in a supportive environment. At a minimum, PHR and consumer empowerment should be on the agenda for discussion in every HIE, or the backlash could be one of albeit many potential factors that limit HIE value.

# Test Your Understanding

. . . using the quiz provided in the handout materials.

Also join us for one or more of our future audio conferences which will cover the remainder of the six courses in the HIE track.

If you are interested in earning the **CPHIE** certification, please visit [www.HealthITCertification.com](http://www.HealthITCertification.com) for information on enrolling in the four core courses and how to take the certification exam.

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This course has described the landscape of PHRs, especially with an eye toward how they fit in the HIE environment. They represent an important element in the overarching structure of a value-driven health care system, and a natural progression from consumerism in general. A new age, a new generation, and much new technology are available. The task now is to make the most of the opportunities to achieve the best results.

Use the quiz in the handout materials to test your understanding of the content just presented. Answers are provided following the quiz.