

Patient Health Information Management: Searching for the Right Model

by Kamila Smolij, MS, and Kim Dun, MD, PhD

Abstract

Accurate and timely health information is a crucial element in the medical decision making process during a medical encounter. Inadequate or misleading patient health information can lead to medical errors, inaccurate decision making, and increased cost. Providing physicians with access to every detail of a patient's medical history is difficult. Striking the balance between adequate and effective amounts of information is difficult. The Personal Health Record and Continuity of Care Record have emerged as concepts to support that balance.

This paper reviews recently published literature on (1) approaches to personal health information management, (2) distinctions between terms and definitions describing patient health information, its format, its availability, and its accessibility, (3) guidelines, studies, or standards to support the rationale of patient information data elements that should be available to the provider for any medical encounter, and (4) identification of the most important needs for patient health information that should be addressed. The purpose of the review is to clarify the benefits and detriments of the different approaches as well as to provide some recommendations for the right model of patient health information management, focusing on the idea of the appropriate health information being available when needed.

Keywords

ASTM Continuity of Care Record, Personal Health Record, Patient Health Information, HL7 Clinical Document Architecture, HL7 Electronic Health Record Functional Model, Electronic Medical Record, Electronic Patient Record, Computer-based Patient Record

Introduction

Recently, much attention has been paid to interoperability of medical record systems to allow patient information to be available, accessible, and shared across organizations and with the patient. When President Bush, in his State of the Union Address on January 20, 2004, announced his plan to ensure that most Americans have electronic health records within the next ten years, he laid out a framework for this effort and underscored the importance of making patient health information electronically available "at the time and place of care, no matter where it originates."¹ Over a year later, the National Committee on Vital and Health Statistics (NCVHS) responded to President Bush's vision with a report on Personal Health Record (PHR) systems that "describes initial findings from national hearings covering the many types of systems referred to as 'Personal Health Records,' suggests areas for further exploration, and offers twenty recommendations for...[President Bush's] consideration."² In this letter, the NCVHS pointed out that "there is no uniform definition of 'personal health record' in industry or government, and

the concept continues to evolve. Experts often use the concept of the PHR to include the patient's interface to a healthcare provider's electronic health record. Others consider PHRs to be any consumer/patient-managed health record. This lack of consensus makes collaboration, coordination and policymaking difficult."³ The ever-increasing number of different products available on the market, emerging new standards, and the disparities among healthcare institutions only add to the complexity of the matter. Therefore, the purpose of this paper is to clarify and categorize different approaches to the idea of having the appropriate patient health information available when needed and to recommend the best model.

Background

The Institute of Medicine (IOM) estimates that of the 98,000 Americans dying each year from preventable medical errors, one-fifth of these errors are linked to the lack of prompt access to patient health information.⁴ Recent experiences with disasters like Hurricane Katrina caused the disappearance of thousands of medical records.⁵ Patients also commonly leave clinics with no tangible information about their medications, goals, or plan of treatment.⁶ Therefore, it is important to review the literature to determine the best approach to patient health information management and to recommend a model that would address the problems mentioned above.

Process for Selecting Material

The aim of the search was to find the most recently published articles on the subject of patient health information management. In order to concentrate the search on electronic health records and their availability, we used the terms *electronic, patient, health, information, availability, and record* to search the Internet. The Google search produced 25,100,000 items, and the PubMed search produced 33 items. From the initial review, we were able to select terms pertaining to patient health information management that were most frequently addressed in these articles: *Electronic Health Record (EHR), Electronic Patient Record (EPR), Electronic Medical Record (EMR), Personal Health Record (PHR), ASTM Continuity of Care Record (CCR), Patient Medical Record Information (PMRI), interoperability, Master Patient Index, Regional Health Information Organization (RHIO), Health Information Exchange (HIE), Smart Cards, Health Information Management (HIM), Medical Internet, Computerized Patient Record (CPR), Computer-based Patient Record (CPR), and Computerized Medical Record (CMR)*. We used each of these terms to obtain articles to further explore each of these concepts. By reviewing the findings, we were able to determine that some of these terms are used interchangeably to describe the same or similar concepts. We were also able to select seven terms that represent different approaches or serve different roles in the process of patient health information management.

Body of Review

There are thousands of articles proposing different types and methods of making patient health information available. Many terms are used to describe these methods.

Table 1 presents terms and definitions pertaining to patient health information storage and management. The first three terms (*ASTM CCR, HL7 CDA, and HL7 EHR System Functional Model*) represent standards. The first standard (ASTM CCR) focuses on the content of patient health information, and the second (HL7 CDA) focuses on the format of patient health information.⁷ ASTM (American Society for Testing and Materials) International is one of the largest voluntary standards development organizations in the world—a trusted source for technical standards for materials, products, systems, and services. Health Level Seven (HL7) is an ANSI-accredited, not-for-profit standards-development organization whose mission is to provide standards for the exchange, integration, sharing, and retrieval of electronic health information; support clinical practice; and support the management, delivery, and evaluation of health services. Since we were trying to determine what information should be available rather than how it should be formatted, we focused on ASTM CCR. The third standard (HL7 EHR System Functional Model) “provides a reference list of functions that may be present in an Electronic Health Record System (EHR-S).”⁸ A document discussing this standard points out that there are a number

of definitions pertaining to EHR and that the standard will not create a new definition but “utilize existing definitions that include the concept of EHR Systems as a system (at least one) or a system-of-systems that cooperatively meet the needs of the end user.”⁹ The next terms (*EHR*, *EMR*, *CPR*, *EPR*) represent different types of electronic patient health records created and maintained by healthcare institutions. The last term (*PHR*) represents patient health records maintained by a patient or healthcare consumer. Concentrating on the idea of what patient information should be readily available, we divided these concepts into three categories representing three models of patient health information management: (1) the electronic health record group model (*EHR*, *EMR*, *CPR*, *EPR*), (2) the Personal Health Record (*PHR*) model, and (3) the Continuity of Care Record (*CCR*) model.

The Electronic Health Record Group Model

Although there are differences between Electronic Health Records (*EHR*), Computer-based Patient Records (*CPR*), Electronic Medical Records (*EMR*), and Electronic Patient Records (*EPR*), all these terms describe systems that provide a “structured, digitized and fully accessible [patient] record.”¹⁰ (See Table 2.) The main idea behind these systems is that they will be linked together by a patient identifier. Unfortunately, it is very unlikely that the concept of national patient identifiers will be ever accepted in this country.¹¹ Without such identifiers, a full interoperability between different systems would be very complex and realistically unachievable. Therefore, each patient usually has several disconnected electronic or paper medical records, with duplicated or incomplete information. In addition, the lifelong accumulation of health information may have little value to the current caregiver yet may violate the patient’s privacy.¹²

The Personal Health Record (PHR) Model

The Personal Health Record represents another approach to patient health information, putting the patient in the driver’s seat for managing health information.¹³ (See Table 3.) The common operational method is that a patient chooses one of the many PHR products available.¹⁴ These PHR products may differ by cost, interface, security, storage methods (Web-based, desktop-based, portable devices), and terms and conditions of service.¹⁵ Depending on the specifics of the chosen product, either the patient or a designated/authorized person enters or collects the patient’s health information. There are also products offered by the patient’s health insurance plan or employer. For example, a patient’s health insurance plan has knowledge of the patient’s medical activities from claims, which can significantly improve the workflow of managing patient health information.¹⁶ Thus, the PHR may be a way of coordinating (managing) a patient’s otherwise dispersed health records. Different products have different characteristics, but according to the Markle Foundation Connecting for Health, a PHR should have the following characteristics:

1. Patient-controlled
2. Contains patient’s lifetime health information
3. Contains information from all healthcare providers
4. Accessible anytime and anywhere
5. Private and secure
6. Transparent (traceable access and editing)
7. Interoperable¹⁷

Some of the characteristics are difficult to achieve. For example, characteristics 2, 3, and 7 are limited by the individual’s ability to track all the past health information and by the limited interoperability of current health information systems.¹⁸ The fact that the patient controls his or her PHR can also be problematic. Tang et al. point out that “it is unlikely that a stand-alone PHR that depends solely on patient input can act as a trusted conduit for transmission of medical record data among clinician offices or health care institutions” and that “while patient-entered segments are desirable for some information and only patients can provide some types of health data, clinicians must also have access to their own past considerations and interpretations, as well as have reliable objective data, if they are to depend on records

for clinical decision making. The reliability of patient-entered data depends on the nature of the information per se, the patient's general and health literacy, and the specific motivations for recording the data."¹⁹ Hence the authorship of the PHR is a limiting element and must be addressed accordingly.

ASTM Continuity of Care Record (CCR) Model

There are many EMR, EHR, and CPR systems in use, and there are many healthcare entities that still use paper-based health records. There is a need for a standard that will precisely define what information should be recorded and how it can be transported so that all the systems can interoperate in handling patient health information. The ASTM CCR (see Table 4) was developed to store the most relevant patient information electronically and make it available to all providers, systems, and patients that require this information.²⁰ An important aspect of the ASTM CCR is that it is technology neutral.²¹ It is an XML-based system; therefore, it is human- and machine-readable and can be displayed in variety of formats (html, Microsoft Word document, or PDF file).²² Another important aspect is its validity: the CCR can be completed only by authorized healthcare personnel.²³ It is also important to understand that the CCR is not a clinical document but a collection of clinical documents to summarize information from one or many existing patient health information systems.²⁴

Discussion

Based on the reviewed articles, it becomes clear that terms obtained from the initial search fall into three categories:

1. The clinician-controlled, electronic patient health record (CPR, EHR, EMR), owned by a particular healthcare entity (provider, clinic, practice, hospital, etc.), offers limited interoperability and external access but great reliability and a number of useful and helpful functionalities. Although it may be a source of comprehensive patient health information, the limited interoperability may cause a lack of coordination of the patient's healthcare records. This in turn leads to the currently common situation where a patient has a number of uncoordinated, dispersed paper and electronic health records, lacking one that is reliable and up-to-date, containing the information most relevant to the healthcare provider at any point of care.
2. A patient-controlled, patient-owned, and patient-managed Personal Health Record (PHR) can serve as the coordination vehicle among various sources (records) of patient health information. The patient can obtain his or her health information from various healthcare providers and continually update the PHR. However, patients may not be very diligent about updating the PHR or may use their own judgment about what should or should not be included in the PHR. Therefore, this makes the PHR model highly unreliable and its validity and value questionable.
3. The ASTM Continuity of Care Record (CCR) is the depiction of patient health information at any given time. It is updated by a provider at the conclusion of a medical encounter. The standards clearly define what type of information should be included in a CCR instance. Some of the data are required; some are optional. The provider decides which of the optional data are relevant and should be included. The patient's most recent CCR can be printed, faxed, transmitted electronically, or made available on the Internet. It appears to be the best model to make the patient's most relevant health information available and trustworthy for any provider at any point of care.

Conclusion

There is no one single perfect model or approach cited in the reviewed literature that would handle all aspects of patient health information. It is worth mentioning that every healthcare institution manages a health record (mostly paper-based) for each of its patients. The electronic health record adds many dimensions to the management of patient health information within the healthcare institution. However, the limited multi-enterprise interoperability requires other methods of coordinating patient health

information. This is when the other models come into play. When patients embark on the task of managing their own health information, they can use one of many Personal Health Record products available to facilitate this process. Unfortunately, the reliability and validity of the end product can cause it to be of limited value to a provider. The ASTM CCR takes care of this problem by placing the provider in charge of creating the patient's health summary after every encounter and by clearly defining the content of the document. The versatility of how a CCR can be accessed and transported across different platforms and institutions makes it a valuable model for managing patient health information.

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Notes

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Table 1
Patient Health Information—Terms and Definitions

Term	Definition
ASTM Continuity of Care Record (CCR)	“The ASTM CCR standard is a patient health summary standard, a way to create flexible documents that contain the most relevant and timely core health information about a patient, and to send these electronically from one care giver to another. It contains various sections—such as patient demographics, insurance information, diagnosis and problem list, medications, allergies, care plan, etc.—that represent a ‘snapshot’ of a patient’s health data that can be useful, even lifesaving, if available when patients have their next clinical encounter. The ASTM CCR standard is designed to permit easy creation by a physician using an electronic health record software program (EHR) at the end of an encounter.” ¹
HL7 Clinical Document Architecture (CDA)	“The HL7 Clinical Document Architecture (CDA) is a document architecture standard designed to represent medical legal health care encounter documents in a standardized format. CDA r2 (Release 2) was balloted and approved in June 2005.” ²
HL7 EHR System Functional Model	“The HL7 EHR System Functional Model and Standard Draft Standard for Trial Use (DSTU) is intended to provide a summary understanding of functions that may be present in an Electronic Health Record System (EHR-S), from a user perspective, to enable consistent expression of system functionality. This EHR-S Model describes the behavior of a system from a functional perspective and provides a common basis upon which EHR-S functions are communicated. The DSTU can help vendors describe the functions their systems offer, and help those planning new purchases or upgrades to describe the functions they need.” ³
Computer-based Patient Record (CPR)	“Computer-based Patient Record is a compilation in electronic form of individual patient information that resides in a system designed to provide access to complete and accurate patient data, alerts, reminders, clinical decision support systems, links to medical knowledge, and other aids.” ⁴
Electronic Health Record (EHR)	“The Electronic Health Record (EHR) is a secure, real-time, point-of-care, patient-centric information resource for clinicians. The EHR aids clinicians in decision-making by providing access to patient health record information when they need it and incorporating evidence-based decision support. The EHR automates and streamlines the clinician’s workflow, ensuring all clinical information is communicated, and ameliorates delays in response that result in delays or gaps in care. The EHR also supports the collection of data for uses other than clinical care, such as billing, quality management, outcomes reporting, and public health disease surveillance and reporting.” ⁵
Electronic Medical Record (EMR)	“Electronic Medical Record—A computer-based patient medical record. An EMR facilitates access of patient data by clinical staff at any given location; accurate and complete claims processing by insurance companies; building automated checks for drug and allergy interactions; clinical notes; prescriptions; scheduling; sending to and viewing by labs. The term has become expanded to include systems which keep track of other relevant medical information. The practice management system is the medical office functions which support and surround the electronic medical record.” ⁶

Electronic Patient Record (EPR)	“Electronic Patient Record (EPR) describes the record of the periodic care provided mainly by one institution. Typically this will relate to the healthcare provided to a patient by an acute hospital.” ⁷
Personal Health Record (PHR)	“The Personal Health Record (PHR) is an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider.” ⁸

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Table 2
CPR, EHR, EMR, EPR Summary

Terms	Computer-based Patient Record (CPR), Electronic Health Record (EHR), Electronic Medical Record (EMR), Electronic Patient Record (EPR)
Purpose	“Provides secure, reliable, real-time access to patient health record information where and when it is needed to support care. Captures and manages episodic and longitudinal electronic health record information. Functions as clinicians’ primary information resource during the provision of patient care. Assists with the work of planning and delivering evidence-based care to individual and groups of patients. Captures data used for continuous quality improvement, utilization review, risk management, resource planning, and performance management. Captures the patient health-related information needed for medical records and reimbursement. Provides longitudinal, appropriately masked information to support clinical research, public health reporting, and population health initiatives. Supports clinical trials and evidence-based research.” ¹
Owner (who enters information)	Authorized clinicians and healthcare personnel
Information included	“Captures and manages episodic and longitudinal electronic health record information.” ² “Data [are] used for continuous quality improvement, utilization review, risk management, resource planning, and performance management.” ³
Interoperability	There are some standards (CCR, HL7) required for full interoperability between different systems; or, for multiprovider, multispecialty, and multisystem interoperability, a concept patient identifier would be required. ⁴
Accessibility	The accessibility of patient health information depends on the product and the healthcare organization.

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Table 3
PHR Summary

Term	Personal Health Record (PHR)
Purpose	“Enable[s] people electronically to manage their health information and that of others for whom they are authorized.” ¹
Owner (who enters information)	Patient or institutions associated with patient (e.g., payer or employer)
Information included	<p>Personal information Family medical history Immunization history and planner Allergies to food and drugs History of personal illnesses or past procedures Medications and supplements Contact information for other healthcare practitioners, clinics, etc.</p> <p><i>Additional optional or possible information:</i> Vital signs recording Graphing and trending of health data Visit information Lab and radiology results Medical record security audit Mental illness history Discharge summaries Daily living habits (smoking, diet, exercise, etc.) Drug interaction checks Health goals and planning Reputable medical education sources Links to other healthcare services Medical information resources (such as a medical test handbook that provides a listing and description of different medical tests) Listings of healthcare providers in local areas Scheduling functions and appointment requests Reminders or e-mail notification of appointments Live data exchange with healthcare practitioners Online communities and chat rooms Event listings Product shopping Emergency card or member card IDs²</p>
Interoperability	Depends on the particular product
Accessibility	Depends on the particular product

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Table 4
CCR Summary

Term	ASTM Continuity of Care Record (CCR)
Purpose	“The goal is to create a CCR that will enable the next provider to easily access the information . . . at the beginning of a first encounter and easily update the information when the patient goes on to another provider, in order to support the safety, quality, and continuity of patient care. The CCR may be used as a vehicle to exchange clinical information among providers, institutions, or other entities. It may also be used by the patient as a brief summary of recent care.” ¹
Owner (who enters information)	“The CCR will be completed by physicians, nurses, and ancillary providers (e.g., social work, physical therapy, occupational therapy) upon referral or transfer or other transition of a patient from one caregiver to another, whether it is outpatient, inpatient, or community based.” ²
Information included	<p>Provider information</p> <p>Patient identifying information</p> <p>Patient insurance and financial information</p> <p>Health status of the patient</p> <ul style="list-style-type: none"> ▪ Diagnoses, problems, conditions ▪ Adverse reactions, alerts ▪ Current medications ▪ Immunizations ▪ Vital signs ▪ Laboratory results ▪ Procedures/assessments ▪ Optional extensions <p>Care documentation</p> <p>Care plan recommendations³</p>
Interoperability	The CCR supports full semantic and computational interoperability (object-oriented data model using an XML-defined data object-attribute approach). ⁴
Accessibility	XML coding is required when the CCR is created in a structured electronic format. The XML coding “provides flexibility that will allow users to prepare, transmit, and view the CCR in multiple ways, for example, in a browser, as an element in a Health Level 7 (HL7) message or CDA compliant document, in a secure email, as a PDF file, as an HTML file, or as a word processing document. It will further permit users to display the fields of the CCR in multiple formats.” ⁵

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