



HIMSS Personal Health Records Definition and Position Statement

Prologue

To enable the goals of reducing medical errors, improving quality of care, and improving the validity of information available to care providers, Personal Health Records (PHRs) function to consolidate an individual's medical information in one place. Recognizing the potential benefits of PHRs, HIMSS works with national consumer-based healthcare organizations to help educate and facilitate the adoption of PHRs. In so doing, HIMSS has taken an active role to facilitate interest in and discussion around this important topic.

PHRs historically have been maintained by individuals in paper form or in unstructured documents on personal computers. More recently, structured *electronic* PHRs (ePHRs) have become available in a variety of formats, and many are Internet-linked with data entered and maintained by the individual or "tethered/connected" to a single specific healthcare, insurance, or other organization that maintains an individual's health records. Some tethered/connected ePHRs are hybrids allowing some information to be entered by the individual. Also, there is an evolution toward interoperable Internet ePHRs that cull all health information relative to the individual who is also responsible for his/her ownership and management.

This document defines an interoperable electronic Personal Health Record, or ePHR, recognizing that this is not the current state of ePHRs but is an appropriate direction for development. It contains guiding principles for ePHR development, and is the work of the HIMSS Personal Health Record Steering Committee and its work groups: Defining the ePHR Work Group and the National ePHR Discussion Work Group.

Statement of Position

HIMSS supports the development of interoperable ePHRs which are interactive and use a common data set of electronic health information and e-health tools. HIMSS envisions ePHRs that are universally accessible and layperson comprehensible, and that may be used as a lifelong tool for managing relevant health information that is owned, managed and shared by the individual or his or her legal proxy(s). The ideal ePHR would receive data from all constituents that participate in the individual's healthcare; allow patients or proxies to enter their own data (such as journals and diaries); and designate read-only access to the ePHR (or designated portions thereof).

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HIMSS supports ePHR applications with the following characteristics:

- Provide for unique patient identification;
- Allow secure access to the information contained in the ePHR;
- Permit the receipt of email alerts that do not reveal protected health information (PHI);
- Allow patient proxy(s) to act on behalf of the patient;
- Permit the designation of information to be shared electronically; and,
- Provides technical support to ePHR constituents at all times.

HIMSS champions the development of national standards to ease burdens placed on constituents due to variances in state law and the development of national and uniform state standards to address legal concerns raised by ePHRs such as reliability, reimbursement, ownership, access, transfer, and the limitations, rights and responsibilities of patients and providers for the use of e-health and ePHRs.

Similarly, HIMSS encourages the adoption of incentives by payors, providers, pharmaceutical companies, device manufacturers, and the federal and state governments of the United States to reduce the financial barriers to motivate widespread ePHR adoption.

ePHR Definition

HIMSS defines an ePHR as follows:

An electronic Personal Health Record (“ePHR”) is a universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promoting health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and e-health tools. The ePHR is owned, managed, and shared by the individual or his or her legal proxy(s) and must be secure to protect the privacy and confidentiality of the health information it contains. It is not a legal record unless so defined and is subject to various legal limitations.

HIMSS’ definition is meant to address the immediate and future developmental direction of ePHRs, with the understanding that any ePHR definition is not static and will evolve with future technology advances and further adoption of electronic health records (EHRs)/electronic medical records (EMRs) and ePHRs that will create shifts in the culture surrounding the utilization and demand of ePHR constituents.

The ePHR technology providers are encouraged to design applications that meet the needs of the patient; however, technology providers do have a responsibility to clearly define the purpose and intent of how the technology should be used. Likewise, it is the patient’s responsibility to understand how the ePHR may function, including, but not limited to, the use and exchange of information in order to exercise one’s choice of participating or not participating in a specific ePHR application.

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ePHR should include the following characteristics listed by constituency class:

- The individual about whom the ePHR relates:
 - The proxy(s), or individual(s) who is/are the legally authorized representative(s) of the patient as determined by state law, such as a parent or legal guardian if the patient is a minor;
 - A legal guardian if the patient has been adjudicated incompetent to manage the patient's personal affairs;
 - An agent of the patient authorized under a durable power of attorney for healthcare;
 - An attorney *ad litem* (guardian of the suit) appointed for the patient;
 - A guardian *ad litem* appointed for the patient;
 - A personal representative or statutory beneficiary if the patient is deceased; or
 - An attorney retained by the patient or by another person listed above;
- The healthcare provider or healthcare institution, such as hospitals, laboratories, nursing facilities, imaging facilities, pharmacies, physicians, physician groups, nurses, nurse practitioners, and other licensed healthcare professionals, etc.;
- Payors, such as individuals, employers, insurers or benefit plans who pay for healthcare; and
- Emergency responders and emergency receivers.

ePHR Models

HIMSS supports ePHR models wherein data within an ePHR can be imported from other applications, (e.g., an EHR/EMR), entered by the patient, or another individual to whom the ePHR owner has granted data entry access, or uploaded from devices. Further, HIMSS supports ePHR models that allow consumers to export data from their ePHR (portability) and allow providers, with patient/proxy consent, to export data out of ePHRs or mine data from ePHRs for legitimately defined purposes, such as population health research or health trend analysis.

The current forms of ePHRs in the market mainly involve three basic models:

- Software utilized by individuals to enter and maintain their personal health information;
- Web sites that are maintained by third parties which allow patients to enter and access their information; and
- Websites that allow patients to view information from other applications such as an institutional EMR/EHR, or from an application that maintains the individual's health insurance claims data.

The latter is referred to as a *tethered/connected* ePHR. These models are not mutually exclusive, and in a tethered/connected model, the patient may have the ability to enter data into the ePHR.

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Challenges to the adoption of the tethered/connected model depend on the application owner organization.

- In a tethered/connected ePHR model, the ePHR is integrated with another application, such that the application owner organization:
 - Provides the ePHR to the patient as an electronic portal;
 - Loads selected PHI into the patient's ePHR;
 - Provides e-health services via the ePHR; and
 - Owns and manages the ePHR, allowing patient access.

Note: The ePHR in this model is not comprehensive and is not a legal medical record.

If the ePHR is tethered/connected to the EHR/EMR of a provider organization, the challenges to adoption include:

- The current slow adoption of EMRs by medical practices; and
- Provider concerns including:
 - Sharing of inappropriate information with patients;
 - Resultant increased workload;
 - Patient understanding/literacy of the data;
 - Potential payor contract requirements mandating participation.

If the ePHR is tethered/connected to patient health information applications maintained by insurers or employers, the challenges to adoption include:

- Patient concerns regarding their privacy, and their concerns about such organizations and employers becoming involved in health-related directives rather than such directives coming from their providers.

In an *untethered/disconnected* ePHR model, only the patient, or individuals that have been granted access by the patient, has/have the ability to enter PHI into the ePHR.

At present, these models do not support interoperability, allowing patients to freely transfer their self-entered PHI from an untethered/connected application to a tethered/connected ePHR, or allowing patients to direct the flow of their PHI between the various applications where it resides including the applications from the various providers where the patient may receive care, and from other organizations involved with their healthcare such as insurers and pharmacies. HIMSS encourages the adoption of ePHRs that support interoperability of common standards and international compatibility.

There are multiple sources from which a consumer may obtain an ePHR, such as healthcare providers, employers, health plans, the government, Internet sites, pharmacies, disease management vendors, or device manufacturers, whether tethered/connected or untethered/disconnected. HIMSS champions the development of a universally-accepted ePHR model that would allow patients to:

- Receive data from all constituents that provide or participate in their healthcare;

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- Enter their own data (such as journals and diaries);
 - Designate read access to the ePHR (either by portion or in its entirety);
 - Upload designated portions of their ePHR to interested constituents' electronic systems;
 - Provide log of both information shared and information recorded (or entered into the ePHR), including an audit trail of who has entered, accessed, or modified the information; and
 - Have access to the privacy policy of the source or offerer of the ePHR.

Privacy, Security and Trust

The HIMSS ePHR definition calls for the adherence to current and future privacy and security methods and standards, as well as addressing the issue of patient “trust” or confidence that the PHI supplied will not be used for purposes other than the intended use (referred to as *secondary use of data*) without the explicit permission of the ePHR owner. To the extent that an entity offering an ePHR is not a covered entity under HIPAA or other privacy and security laws, HIMSS encourages the entity to adopt at a minimum the privacy and security standards of HIPAA as if the organization was a covered entity. HIMSS champions ePHR applications that allow patients to:

- Have unique identification;
- Securely access the system;
- Receive alerts via email that do not contain confidential PHI;
- Provide access to other individual(s) authorized by the patient as a proxy to act on his or her behalf should the need arise;
- Provide an audit trail of all information accessed in the ePHR;
- Designate information to be shared electronically with the patient's consent.
- Access the privacy policy of the source or offerer of the ePHR.

HIMSS encourages the development of ePHRs that address the most current federal and state privacy and security regulations, including but not limited to, administrative, physical, and technical safeguards. This will enable the clinician/provider of care to comply with laws and regulations that proscribe the circumstances under which PHI may be disclosed without patient authorization. A HIPAA Notice of Privacy Practices must be a part of the ePHR application to enable clinician/provider compliance. Furthermore, to be in compliance with laws and regulations, the ePHR must include standards on secondary uses of patient data.

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Common /Uniform/Minimum Data Set

Although there is currently a lack of universal data element standards for ePHRs, HIMSS champions the development of ePHRs with the following minimum data set, which would include an individual's current and historical health and personal information:

- Personal identifier
- Clinical summary
 - Active prescribed medications (generic nomenclature is required)
 - Historical prescribed medications and reason for discontinuation (generic nomenclature is required)
 - Other current non-prescribed (over the counter) medications
 - Allergy information
 - Diagnoses/problem list
 - Immunization status
- Results/reports
- Histories
 - Immunization history
 - Past medical history
 - Surgical history
 - Family history
 - Social history
- Contact and registration information
 - Current address information and guarantor information
 - Healthcare durable power of attorney and proxy designees
 - Provide stored copy of durable power of attorney
 - Emergency contact(s)
 - Primary care physician
 - Other providers of care
- Current and historical insurance information

eHealth Tools

HIMSS encourages the development of ePHRs that provide an array of patient health tools that empower patients to make better personal healthcare decisions, comply with their healthcare regimen, improve the quality of their outcomes, and improve the efficiency of healthcare services. Specifically, these tools help patients maintain health and wellness, as well as manage chronic diseases. The tools must:

- Be simple to use through the application of appropriate human factors standards in user interface design;
- Be in non-clinician terms and be appropriate for an eighth grade reading level; and

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- Employ both a “pull” and “push” content model where a patient can pull content from reliable resources and also allow the patient’s providers to push information to the applications.

Examples of patient health tools include:

- ePHR usage and training materials
- Health maintenance
- Wellness and disease management
- Device data entry and display
- Provide current medical trialiInformation based on diagnosis
- Diagnosis-based educational materials
- Services
 - Appointment scheduling
 - Prescription renewal
- eRefills (ability to communicate with a pharmacy to have refills delivered along with the ability to share this information with the original prescribing provider)
- eVisits
 - Information therapy
 - Education
 - Physician remote online care
- Interactive messaging
- Messaging transparency of healthcare institution and provider reports related
 - Quality
 - Cost
 - Statistics

Technical

HIMSS champions the development of ePHRs providing technical assistance, such as online help that must be available to assist constituents in the use and navigation of the ePHR, as well as addressing security issues and recommendations, such as automatic logoffs, cache clearing, firewalls, anti-virus software, password standards, etc.

In addition, HIMSS encourages the development of ePHRs that provide technical support by telephone; ideally, this support would be available 24 hours a day, seven days a week.

Legal

As with EHRs, HIMSS acknowledges that there are a myriad of legal barriers to widespread ePHR adoption. HIMSS recommends development of national standards to ease burdens placed on constituents due to variances in state law and/or the development of national and uniform state rules, regulations and/or standards to address legal concerns raised by ePHRs, such as

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ownership, access, control, reimbursement, rights and duties of constituents, limitations and liabilities raised by data quality, and privacy and security.

HIMSS supports ePHRs that have the ability to incorporate patient-entered data into their provider's legal medical record if the provider so chooses.

HIMSS acknowledges if a provider loads data from an EHR/EMR into a patient's ePHR, or if a patient uploads data from an ePHR into a provider EHR/EMR ePHR, legal issues are raised including, but not limited to:

- Patient responsibility for accurate and complete data entry and transfer
- Provider responsibility for reviewing patient entered data
- Reimbursement for provider-patient interaction through the ePHR

- Insurer responsibility
 - Reimbursement
 - Access
 - Transfer
 - Accuracy of data

- Rules and regulations
 - Reimbursement
 - Liability issues
 - Ownership issues

- Patient rights such as access, accounting, and amendment

- Liability for eHealth services and disclaimers regarding the limitations, rights, and responsibilities of patient and provider for e-health services

- Evolving definitions of legal medical records

- Variance between state laws
 - Directives
 - Authorized representative
 - Telemedicine
 - Unauthorized practice of medicine

- Interstate e-health services

HIMSS also supports ePHRs containing useful legal patient documents such as:

- Authorizations, advance health directives, consent forms and powers of attorney that specify who has access to the patient's PHI;

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- Contact information such as for next of kin, legal counsel, guardian or *Ad Litem*; and
 - Insurance information.

Medical Liability

Medical liability issues include, but are not limited to, the following:

- Holding a physician liable for more than the ordinary standard of care based on a “reasonable review” of a standard formal PHR;
- Holding a physician liable for providing care based on incomplete or inaccurate information contained in a PHR;
- Holding a physician liable for the act of consulting with a patient who lives in a state other than that in which the physician is licensed.

HIMSS supports that **no** additional barriers to clinician adoption of PHRs be created in addressing these liability issues, such as requiring additional eHealth liability coverage or licensure, or as otherwise addressed in this document.

Financial

HIMSS supports the adoption of incentives by all constituents, including patients, payors, healthcare providers, healthcare institutions, pharmaceutical companies, device manufacturers and the federal and state governments of the United States to reduce the financial barriers to widespread ePHR adoption.

A barrier to ePHR adoption is the identification of a constituent who will fund the substantial costs of ePHR development, implementation, support, and maintenance. To date, the appropriate funding source to enable the widespread adoption of ePHRs in the United States has not emerged. ePHRs “tethered” to an institutional EHR/EMR are often offered as a market differentiator for provider institutions to attract new patients and create stronger liaisons with their patients. Such models are financed by the provider institution. This model, however, would serve as a disincentive to interoperable stand alone ePHRs that incorporate the pertinent individual’s lifetime health information and encourage individuals to seek care at institutions with the best outcomes. Members of the constituent groups who presently provide ePHRs include all participants in the U.S. healthcare system: providers, payors, vendors, pharmaceutical companies, device manufacturers, the state and federal governments of the United States, etc. Studies of ePHR benefits of the various ePHR models will help to determine appropriate ePHR future ePHR funding.

Physician adoption of ePHRs is enhanced through the ability to do e-visit billing for ePHR “encounters,” and through the creation of time-saving clinician practice efficiencies through ePHR workflow interaction. Further research is required to explore if ePHRs can truly increase clinician productivity, create revenue opportunities, and avoid unnecessary patient visits.

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Summary

HIMSS supports the design and development of ePHRs as a tool that empowers healthcare consumers to manage and improve their health, positively influence behavioral decisions affecting health, enhance communication and a sense of partnership with health consumers and their health providers, and ultimately lower healthcare costs across our nation.

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