TECHNICAL
REPORT

ISO/TR
14292

First edition
2012-03-15

Health informatics — Personal health records — Definition, scope and context

Informatique de santé — Dossiers de santé personnels — Définition, domaine d'application et contexte

Reference number
ISO/TR 14292:2012(E)

ISO copyright office
Case postale 56 • CH-1211 Geneva 20
Tel. + 41 22 749 01 11
Fax + 41 22 749 09 47
E-mail copyright@iso.org
Web www.iso.org

Published in Switzerland

Contents

Foreword

ISO (the International Organization for Standardization) is a worldwide federation of national standards bodies (ISO member bodies). The work of preparing International Standards is normally carried out through ISO technical committees. Each member body interested in a subject for which a technical committee has been established has the right to be represented on that committee. International organizations, governmental and non-governmental, in liaison with ISO, also take part in the work. ISO collaborates closely with the International Electrotechnical Commission (IEC) on all matters of electrotechnical standardization.

International Standards are drafted in accordance with the rules given in the ISO/IEC Directives, Part 2.

The main task of technical committees is to prepare International Standards. Draft International Standards adopted by the technical committees are circulated to the member bodies for voting. Publication as an International Standard requires approval by at least 75 % of the member bodies casting a vote.

In exceptional circumstances, when a technical committee has collected data of a different kind from that which is normally published as an International Standard ("state of the art", for example), it may decide by a simple majority vote of its participating members to publish a Technical Report. A Technical Report is entirely informative in nature and does not have to be reviewed until the data it provides are considered to be no longer valid or useful.

Attention is drawn to the possibility that some of the elements of this document may be the subject of patent rights. ISO shall not be held responsible for identifying any or all such patent rights.

ISO/TR 14292 was prepared by Technical Committee ISO/TC 215, *Health informatics*.

Introduction

Personal health records (PHRs) are by their very nature hard to define. In order to understand the breadth and depth of PHRs, it might be helpful to consider PHRs and clinical electronic health records (EHRs) as being positioned at two opposing ends of a spectrum of health records (see Figure 1). A PHR could be defined as the direct counterpoint to an EHR, but in practice the lines of demarcation are most often not clear, nor desirable, except when viewed in terms of who has control over the health record and the content within it.

While EHRs have traditionally been defined as “logical representations of information regarding, or relevant to, the health of a subject of care”, they have existed primarily for the purposes of the healthcare organization providing care to an individual. Information from EHRs might be made available to the subject of care or his/her authorized representative, upon request to the clinician who is acting as a steward of the health information. In some countries, this is supported by specific legislation.

PHRs are also “logical representations of information regarding, or relevant to, the health of a subject”; however, in the strictest sense, these health records are primarily managed and controlled by the individual who is the subject of the record, or his/her authorized representative. The individual has rights over the clinical content held within a PHR, including the ability to delegate those rights to others, especially in the case of minors, the elderly or the disabled. The individual, or his/her authorized representative, is the key stakeholder, determining that the content of the PHR is relevant and appropriate. The simplest examples include self-contained mobile phone applications that track a personal diet or exercise history, which are controlled by the individual and accessed only by the individual him or herself.

Healthcare organizations and healthcare systems are accountable for the content of the EHRs they control. Individuals have autonomy over records they choose to keep. However, in between these two strict views of an EHR and a PHR is a continuum of person-centric health records, which might have varying degrees of information sharing and/or shared control, access and participation by the individual and his/her healthcare professionals. Towards the EHR end of the spectrum, some EHRs provide viewing access or annotation by the individual to some or all of the clinician’s EHR notes. Towards the PHR end of the spectrum, some PHRs enable individuals to allow varying degrees of participation by authorized clinicians to their health information, from the simple viewing of data to the control of part or all of the PHR.

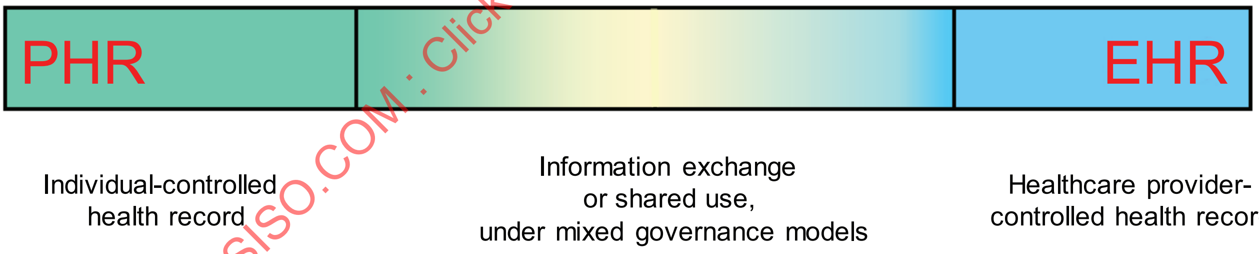

Figure 1 — The PHR-EHR spectrum

In the middle of this continuum there exists a growing plethora of person-centric health records that operate under collaborative models, combining content from individuals and healthcare professionals under agreed terms and conditions, depending on the purpose of the health record. Control of the record might be shared, or parts controlled primarily by either the individual or the healthcare professional with specified permissions being granted to the other party. For example, a shared antenatal record might be either primarily a PHR, under the auspice of the individual, permitting authorized healthcare professionals to contribute content or directly edit part or all of the record itself, or it might be an extension of an organization’s EHR, permitting the individual to view or directly contribute content to some or all of the record. The exact nature of the sharing of responsibilities and participations by each party needs to be specified in the terms and conditions (governance) of the health record.

Health information with a PHR might be purely for use by the individual him or herself, or might be shared with healthcare professionals and others, such as family members. The inclusion of EHR extracts within a PHR, for example laboratory reports or discharge summaries, is a desired feature of a comprehensive PHR, but in order to preserve data integrity, the PHR might only be annotated with comments by the individual and not edited.

Ownership of a shared PHR can be complicated, requiring differentiation between moral ownership of the health information content and technical/legal stewardship for storing and securing the data. Storage of health information upon a PHR platform that is managed by a third party requires a formal relationship between the two parties so that individuals can assert their rights and the third party can uphold their responsibilities.

The content scope for a PHR varies according to purpose and is broader than most conventional EHRs. In the maximal scope, a PHR might have a breadth that encompasses health, wellness, development, welfare and concerns, as well as a chronological depth that embraces history of past events, actions and services, tracking and monitoring of current health or activities, and goals and plans for the future. Some PHRs will have a very general summary focus; others might be activity-driven, e.g. a diabetes management record within a diabetes community portal or a personal fitness and exercise record. An individual might choose to have a single summary PHR or several activity-driven PHRs, or a combination of both.

Health informatics — Personal health records — Definition, scope and context

1 Scope

This Technical Report defines a personal health record (PHR). This definition is intended to help clarify the kinds of records that should be called PHRs, in recognition of the lack of consistency in how this term is presently used. This Technical Report considers the PHR from the perspective of the personal information contained within it and the core services needed to manage this information.

A PHR is not a singular entity; the concept encompasses a spectrum of possible information repositories and services that meet different purposes consistent with the definition. This Technical Report therefore also discusses the scope of the PHR in terms of this spectrum as a series of dimensions by which a PHR may be classified and equivalent PHR products compared. It also includes one dimension to classify the kinds of collaborative care PHRs provided by healthcare organizations.

This Technical Report also considers the wider context of engagement of individuals in the management of their own health and healthcare, since this engagement is the primary driver for present-day growth of PHR systems and services internationally.

This Technical Report includes:

- a definition of a PHR;
- a pragmatic multidimensional classification of PHRs;
- an overview of the possible ways in which the inclusion and engagement of individuals in managing their health and healthcare impacts on the potential roles of the PHR, including scenarios for collaborative care between individuals and healthcare organizations.

The many kinds of end-user application that might be implemented and used to deliver PHR system functionality are outside the scope of this Technical Report.

2 Terms and definitions

For the purposes of this document, the following terms and definitions apply.

2.1
access control
means of ensuring that the resources of a data processing system can be accessed only by authorized entities in authorized ways

[ISO/IEC 2382-8:1998, definition 08.04.01]

2.2
auditability
property that ensures that any action of any security subject on any security object may be examined in order to establish the real operational responsibilities

[ISO/TS 13606-4:2009, definition 3.3]

2.3
audit trail
chronological record of activities of information system users which enables prior states of the information to be faithfully reconstructed

[ISO 13606-1:2008, definition 3.9]

2.4
authorization
granting of privileges

2.5
care plan
personalized statement of planned healthcare activities relating to one or more specified health issues

NOTE Adapted from EN 13940-1:2007.

2.6
clinical information
health information
information about a person, relevant to his or her health or healthcare

[ISO 13606-1:2008, definition 3.13]

2.7
concept
unit of knowledge created by a unique combination of characteristics

[ISO 1087-1:2000, definition 3.2.1]

2.8
confidentiality
property that information is not made available or disclosed to unauthorized individuals, entities, or processes

[ISO 7498-2:1989, definition 3.3.16]

2.9
data controller
person who determines the purposes of the processing of personal data

2.10
data owner
person having responsibility and authority for the data

2.11
data processing
obtaining, recording or holding personal data

NOTE This includes organising, adapting, altering, retrieving, consulting, using, disclosing, aligning, combining, blocking, erasing or destroying.

2.12
data processor
person who processes personal data on behalf of the data controller

2.13
data subject
living individual who is the subject of personal data

2.14
EHR
electronic health record
information relevant to the wellness, health and healthcare of an individual, in computer-processable form and represented according to a standardized information model

[ISO 18308: 2011, definition 3.20]

2.15
electronic health record repository
database in which EHR information is stored

2.16
electronic health record system
system for recording, retrieving and manipulating information in EHRs

[ISO 13606-1:2008, definition 3.26]

2.17
entity
concrete or abstract thing of interest, including associations among things

NOTE Adapted from ISO/IEC 2382-17:1999, definition 17.02.05.

2.18
entry
documentation of a discrete item of health information

NOTE An entry may, for example, represent the documentation of a clinical observation, an inference, an intention, a plan or an action.

2.19
health issue
issue related to the health of a subject of care, as identified or stated by a specific health care party

[EN 13940-1:2007]

2.20
healthcare
activities, services or supplies related to the health of an individual

2.21
healthcare service
service provided with the intention of directly or indirectly improving the health of the subject(s) of care to which it is provided

2.22
healthcare organization
organization undertaking the delivery of healthcare

2.23
healthcare professional
person authorized by a jurisdictionally defined mechanism to be involved in the direct provision of certain healthcare activities

NOTE Adapted from EN 13940-1:2007.

2.24
organization
unique framework of authority within which a person or persons act, or are designated to act, towards some purpose

[ISO 6523-1:1998, definition 3.1]

2.25
party
natural person or any other entity considered to have some of the rights, powers and duties of a natural person

NOTE Adapted from ISO/IEC 15414:2006, definition 6.5.1.

2.26
persistent data
data which are stored on a permanent basis

[ISO 13606-1:2008, definition 3.40]

2.27
personal data
data relating to an identified or identifiable natural person

2.28
personal health record system
system for recording, retrieving and manipulating information in personal health records

2.29
policy
set of legal, political, organizational, functional and technical obligations for communication and cooperation

[ISO/TS 22600-1: 2006, definition 2.13]

2.30
role
set of competences and/or performances associated with a task

[ISO/TS 22600-1:2006, definition 2.19]

2.31
service
ability of a system to provide a defined set of output information based on a defined set of input information

2.32
subject of care
person scheduled to receive, receiving, or having received health care

[ISO 13606-1:2008, definition 3.49]

2.33
term
designation of a defined concept in a special language by a linguistic expression

[ISO 1087:1990, definition 5.3.1.2]

2.34
terminology system
terminological system
set of terms representing the system of concepts of a particular field

3 Abbreviations

For the purposes of this document, the following abbreviations apply.

EHR	electronic health record
PHR	personal health record
PDA	portable digital assistant (mobile, hand-held computer)

4 Definition of a PHR

4.1 Definition

A PHR of an individual is a representation of information regarding, or relevant to, the health, including wellness, development and welfare of that individual, which may be stand-alone or may integrate health information from multiple sources, and for which the individual, or the representative to whom the individual delegated his or her rights, manages and controls the PHR content and grants permissions for access by, and/or sharing with, other parties.

4.2 Explanation of the definition

An individual might have more than one PHR, possibly for different uses or on different devices, which might or might not be interconnected. The extent to which a PHR is highly organized or not will vary depending upon the kind of product used and the way in which the individual uses it.

The key distinction between the PHR and the EHR is that, in the former, the individual who is the subject of the record is the key stake-holder determining its content and with rights over that content. This might be through the subject personally entering the content, or by the subject authorizing one or more parties or systems to contribute to the PHR, or by the subject authorizing the creation of a PHR on his or her behalf by an organization or person whose anticipated purpose is considered relevant and trustworthy by the subject.

It should be noted that the definition of content covers health, which includes wellness, development and welfare. This scope reflects the ways in which PHRs are being used and is broader than most conventional EHRs: all of these categories of information can also be found in EHRs on some occasions, but the EHR is inevitably scoped to focus on information relevant to the provision of healthcare services. Information that might be relevant for a PHR will include: a history of past events, actions and services; current situations; future projections of plans, expectations, hopes and concerns. The information might only be intended for use by the subject personally, or for sharing with others.

In some instances, the record serves both EHR and PHR purposes, but in these cases, the source of the data (personal or provider) should be clearly distinguishable.

This definition does not imply that the subject is primarily responsible for managing the repository, nor that he or she is the legal data processor or legal owner of the record system on which it is held. [If the individual is the controller, but not the legal owner of the system, this will require that a formal relationship between the two parties be established so that individuals (data subjects) can assert their rights, and the holder can uphold his/her responsibilities].

This definition states that the subject of the record has exclusive rights to determine who has permission to access, add to, or communicate the record contents. The subject may delegate such rights to others. This implies that the subject always has the capability to ensure that the content remains relevant and appropriate in his or her opinion and, therefore, that the subject personally always has such permissions over the whole of the PHR content.

In the case of minors or those not considered able to exercise personal autonomy in healthcare decisions, the carer or guardian may be the individual with control of the PHR content on behalf of the subject of the record.

This definition distinguishes the repositories of personal health information and the core services needed to manage the information in those repositories (the PHR, as defined) from the wider set of applications and services needed to deliver useful functions and features to end users (PHR systems, but which include a PHR as defined above).

Several other published definitions of the PHR are provided and discussed in Annex A.

5 Scope of the PHR

There are many kinds of PHR systems in existence or anticipated, meeting different kinds of needs in order to keep subjects of care informed and engaged in health and social care, or to enable individuals who are not needing or seeking healthcare to keep track of their level of fitness, manage prevention or monitor their health status. This variety of systems and applications is too vast, sophisticated and rapidly changing to be standardized.

The kernel of each of these PHR systems is the personal health information about the record subject, comprising one or more interconnected repositories and a set of computational services that manage (such as create, store, analyse, link, copy, protect, disclose, modify, delete) that information: the PHR.

This clause defines the potential characteristics of the PHR by means of a set of dimensions according to which PHRs can be classified and compared. This classification is not intended to constrain the forward evolution of the PHR, but rather to present the main functions presently supported. It is therefore recommended that this classification be used as a guide rather than as a constraint on the kinds of PHR that are approved or supported within a jurisdiction.

Six dimensions for classification are defined:

a) Dimension 1: Scope of the information

b) Dimension 2: Control over the information

c) Dimension 3: Data processor

d) Dimension 4: Repository auditability

e) Dimension 5: Interoperability and communication

f) Dimension 6: Technical architecture

Each dimension is specified below through a value list describing the main options for how that characteristic might be fulfilled by a PHR. It may therefore be possible to profile any given PHR repository service by means of codes from these PHR Dimensions.

5.1 PHR Dimension 1: Scope of the information

This dimension specifies the kinds of information and information sources reflected in the PHR content. This does not necessarily equate with who has inserted the data into the PHR, or who has access to it, but indicates the authors and professional viewpoints which may be found in that PHR.

For this dimension, more than one value may apply.

Table 1 — PHR Dimension 1

PHR Dimension 1 code	Description
PHR.1.A	Information potentially about a broad range of health topics (including health, health promotion, prevention and surveillance, wellness, welfare) as determined by the subject of the record
PHR.1.B	Information about (and possibly contributed by) family members and other personal contacts of the record subject
PHR.1.C	Information about interactions with carers, voluntary sector, support groups, charities
PHR.1.D	Copies and summaries of health record information
PHR.1.E	Information addressing a specific care team (e.g. social services or occupational health or education services)
PHR.1.F	Information focusing on lifestyle information (e.g. fitness and exercise, nutrition and diet)
PHR.1.G	Information focussed on the management of a particular clinical condition, self-care of specific symptoms or signs or measurements (home monitoring)

5.2 PHR Dimension 2: Control over the information

This dimension specifies the extent of the authority of the subject of the record over the policies that define who can access and modify his or her PHR. The values for this dimension have been ordered to indicate that “A” is the lowest extent of direct control by the individual and “G” is the highest degree of direct control. It should be recognized that the degree of control that might be exerted by the data subject might be constrained by national legislation as well as system capability. In these cases, it is recommended that the system capability be used as the basis for this classification rather than the level of control permitted in its usage settings.

Table 2 — PHR Dimension 2

PHR Dimension 2 code	Description
PHR.2.A	Subject can specify policies applying to a user role or team
PHR.2.B	Subject can specify policies applying to named individuals
PHR.2.C	Subject can specify policies according to purpose of use
PHR.2.D	Subject can specify policies according to usage context (e.g. time periods, locations of access)
PHR.2.E	Subject can specify policies applying to individual documents or entries in the PHR
PHR.2.F	Subject can specify policies that manage access (e.g. permit, deny, revoke, delegate access)
PHR.2.G	Subject can specify policies regarding read, write, modify, export and import functions

5.3 PHR Dimension 3: Data processor

This dimension specifies the party who acts as the data processor of the repository, in a legal sense (for example, registering under data protection legislation) and also operationally. The value chosen here does not imply that the processor is responsible for authorization decisions (this is specified by PHR Dimension 2), but it is possible that the processor is responsible for operationalizing such policies (or for deploying tools and services that permit the parties specified in Dimension 2 to execute such authorizations). For this dimension, only one value will apply for any one PHR repository, although a PHR system might comprise a federation of repositories.

Table 3 — PHR Dimension 3

PHR Dimension 3 code	Description
PHR.3.A	PHR stored by the record subject (e.g. on his or her own computer)
PHR.3.B	PHR stored by vendor of the PHR service or system
PHR.3.C	PHR stored by third party with no commercial interest (e.g. consumer group)
PHR.3.D	PHR stored by a single healthcare organization, such as a primary care centre (general practice), a hospital or a pharmacy
PHR.3.E	PHR stored at a regional/national level by the health service or system
PHR.3.F	PHR stored by an insurer
PHR.3.G	PHR stored by an employer or school or college

5.4 PHR Dimension 4: Repository auditability

This dimension specifies the extent to which the PHR manages its content in ways that meet the kinds of legal requirement expected of an EHR, for example as given in ISO 18308. The quality of managing the repository from this perspective will influence the extent to which the information in it is considered trustworthy for use by health professionals or integration with EHRs.

NOTE If records of health professionals within a PHR are to be trusted as faithful records, the PHR will need to show that the data were entered by the stated professionals and have not subsequently been modified by others.

Four properties are considered: the management of dates and times, of authors, of revision and of audit.

Table 4 — PHR Dimension 4

PHR Dimension 4 code	Description
PHR.4.A	Authors may personally date their entries but no system date is automatically recorded (by implication, there is no time-stamped audit log)
PHR.4.B	Entries are date-time-stamped by the PHR
PHR.4.C	Entries are date-time-stamped and attributed to users by means of self-declaration
PHR.4.D	Entries are date-time-stamped and attributed to authenticated users
PHR.4.E	Entries are date-time-stamped and attributed to users authenticated via an approved registry
PHR.4.F	Entries are date-time-stamped, attributed to authenticated users, and all changes are version-managed (i.e. all changes are documented as time-stamped modifications to a preserved original)
PHR.4.G	Entries are date-time-stamped, attributed to authenticated users, all changes are version-managed, and an audit log of accesses and changes can be viewed by authorized users, including the subject of the record (this might be electronically or, for example, via a printable audit report)

5.5 PHR Dimension 5: Interoperability and communication

This dimension specifies the extent to which the PHR is able to be accessed remotely and is able to share information with other pertinent repositories such as EHRs. This dimension relates to the ability of the repository to support such interoperability and communications, rather than whether they are in operation for a particular PHR or repository. It is therefore primarily concerned with the extent to which the repository supports information and service standards.

NOTE The ability for information within PHRs to be meaningfully integrated with the data within EHRs will also depend upon conformance to clinical data and terminology standards. Once the semantic interoperability challenges for EHRs have been addressed, PHR interoperability can be addressed in a future revision of this Technical Report.

The values for this dimension have been ordered to indicate that “A” is the lowest degree of interoperability and “I” is the highest degree of interoperability.

Table 5 — PHR Dimension 5

PHR Dimension 5 code	Description
PHR.5.A	Local only (proprietary and closed system, e.g. desktop or PDA application not accessible remotely, not communicating externally, or a paper-based record)
PHR.5.B	Remotely accessible (proprietary system but can be accessed from any location, e.g. accessing a Web-based system when on holiday)
PHR.5.C	Proprietary interfaces only (proprietary system capable of export but not conforming to a standard, needs a mapping engine to import the data)
PHR.5.D	Standards-export-capable (proprietary system capable of export conforming to a standard)
PHR.5.E	Standards-import-capable (proprietary system capable of import conforming to a standard)
PHR.5.F	Standards-exchange-capable (proprietary system capable of export and import conforming to a standard)
PHR.5.G	Push-linkable (system has interface to send data directly to other systems, initiated by the subject)
PHR.5.H	Pull-linkable (system has interface to permit any authorized user or system to retrieve data from the PHR)
PHR.5.I	Live-linked (system can both send and receive data from other health or social care systems in real time to maintain concurrency)

5.6 PHR Dimension 6: Technical architecture

This dimension specifies the way in which the PHR has been implemented in terms of the platform and distribution architecture supported. PHRs may be developed and deployed as stand-alone applications with integrated databases, on a computer workstation or mobile device. They may be able to synchronize data between more than one device, or communicate with a Web service that can host the data and enable access from anywhere. These remote repositories might be clones of the local repository, or offer an enhanced range of information and knowledge services.

Table 6 — PHR Dimension 6

PHR Dimension 6 code	Description
PHR.6.A	Local data storage of the PHR via a stand-alone application, accessible only through the application installed on a computer workstation or mobile device
PHR.6.B	Local data storage of the PHR via a stand-alone application, synchronizing between multiple devices (e.g. PDA and home computer)
PHR.6.C	Local data storage of the PHR via a stand-alone application, accessible through the application and also able to be exported by the user to a commonly used non-proprietary format (e.g. document or spreadsheet or HTML)
PHR.6.D	PHR accessible from multiple devices and locations, e.g. via the Web
PHR.6.E	PHR exchanges information with other person-specific healthcare services such as EHRs or test results or scheduling

A more detailed analysis of requirements for PHR systems has been published by HL7 as the Personal Health Record System Functional Model, Release 1. The relationship of this Technical Report to the HL7 System PHR Functional Model is outlined in Annex B.

6 Context of the PHR

6.1 Origins

It is commonplace for people to keep personal notes as an *aide-memoire*, or as a personal record of events, decisions and plans, for any aspect of their lives. People have probably kept personal notes about their health or healthcare for centuries, for example, within their diary or a notebook of some kind dedicated to health history. Sometimes such notebooks are brought into a clinical consultation to help confirm the dates or details of recent health events, or as a record in which to write down any medical instructions given. These have not historically been called PHRs, or been given prominence until recently in the evolution of health records on paper or electronically.

The expansion of interest in products supporting what are now called the PHR needs to be seen as part of an evolving culture of personal autonomy over, and engagement in, aspects of life that were once “left to the professionals”. It has been argued that the PHR has arisen as a consumerist statement, almost a protest against the rather secretive and self-protective behaviour of health professionals and healthcare organizations towards their health records. But it can also be regarded as a natural evolution from the *aide-memoire*, reflecting a trend in society to generally keep better and richer records of many things and the desire to manage these electronically and access them online (such as music collections and bank accounts). They might also be seen as an extension and enrichment of the patient’s engagement as well as a means of informing activities promoted by healthcare systems, pioneered through shared records, such as antenatal record cards, baby immunization books and diabetes home urinalysis booklets, and are potentially now much more broad-ranging, sharing the care of a wide range of conditions, documenting the effects and effectiveness of treatments, or contributing information for clinical research.

In practice, the PHR may be any or all of these things, and this (coupled with the inevitable variations in personal preference) underpins the diversity of what is observed in the healthcare organization and vendor offerings and in the various projects and settings in which PHRs are used. The maturing of portable devices such as PDAs, the evolution of wearable healthcare devices, the adoption of interoperability standards, and the availability of better semantic indexing resources will all contribute to further innovations and no doubt some exciting surprises in the PHR arena.

6.2 Engagement with healthcare services

There are growing evidential, professional, media and legislative pressures to recognize the central role of the public as informed partners in decisions about their personal healthcare, the safety and efficacy of treatment choices and in-service priority setting. People are increasingly expecting to exercise personal and informed autonomy over their healthcare, and it is known that individuals can acquire considerable expertise in managing illness and preventive health if they are given useful and appropriate material with which to educate themselves and the tools with which to participate.

In most countries, residents are being encouraged or are themselves pushing to participate more strongly in the management of their health and healthcare. This engagement is taking many different forms including:

a) monitoring health status and taking measurements that inform long-term disease management;

b) sharing in the decision-making process about treatment;

c) participating in health maintenance and preventive health measures;

d) documenting treatment effectiveness and any side effects;

e) tailoring and adjusting treatments and self care activities within care pathways;

f) deciding where and when to be referred to specialists, and booking appointments;

g) investigating different approaches to care through reading, searching the Web, local and online communities;

h) setting goals and aspirations for future health;

i) complementing conventional treatments with alternative medicine;

j) engaging in personal fitness and wellness programmes;

k) managing payments/benefits/insurance services.

This list provides only a few examples of many areas of engagement emerging globally. Almost all of these require some kind of information sharing, resulting in the provision by many healthcare organizations and some national e-health programmes of online services and portals dedicated to patient/consumer access. Such portals can offer a range of functions including:

— identifying points of contact for health services (physical facilities and providers as well as resources and tools available online);

— access to the appointment system, to change or make appointments (for agreed clinical services);

— requesting repeat (refill) prescriptions and other agreed treatments;

— sending messages to clinical staff, possibly including replies and evolving into an online conversation with the clinician;

— sending messages to pharmacy, possibly including replies and evolving into an online conversation with the pharmacist;

— managing a long-term condition through dedicated applications, for example by contributing monitoring data or uploading data from a portable/wearable device (e.g. BP measures, glucometers, scales, Holter monitors);

— viewing certain kinds of clinical information such as test results, diagnostic X-rays, results of procedures;

— maintaining a shared medical summary;

— completing personal health risk assessment tools and scores;

— access to, and potentially the ability to add to, some kind of organizational EHR;

— “kind of” PHR provided by an organization;

— connectivity to a variety of EHRs (from different providers, pharmacies, laboratories, hospitals, insurers);

— access to consumer-oriented, vetted health education resources and links to approved medical information and education sites;

- social computing resources such as an online forums specific to a certain condition or sub-population.

This list is also only illustrative, and not exhaustive, as the diversity of services being developed and piloted in different care settings is expanding rapidly. These kinds of engagement are stepping stones towards recognizing individuals (and carers, guardians or advocates) as equal players to healthcare professionals in healthcare decision making. It is hoped that this richer engagement will enable individuals to make better-informed health and lifestyle choices, to align their health improvement strategies better with their health professionals, contribute better to the management of long-term conditions and preventive healthcare plans, and to utilize health services more effectively and efficiently for the mutual benefit of the individual and the health system.

Many of these interactions include providing access and/or the ability to contribute to the EHR. In the very long term, the fusion of EHRs and PHRs may occur, as mutual trust and transparency grow. However, at present, and especially considering the variation in the levels of engagement, trust and transparency internationally and across care settings, the PHR will continue to exist and mature for the foreseeable future. Reciprocally, the EHR will probably evolve PHR-like behaviours in recognition of the trend towards a partnership approach to clinical care. This will require its own ethical analysis and a consideration by healthcare professional organizations of the medico-legal and regulatory implications of using PHR information for clinical decision making: trust and accountability. There is a need for further research in this area, and for future policies to specify more clearly how professional accountability and patient accountability are to be managed in the context of shared record information.

In terms of inviting the interaction of the subject of care with the EHR, a spectrum of possibilities can be observed, and the following EHR-Engagement Dimension is offered as a way of classifying the PHR-like properties that might exist in an EHR.

Table 7 — EHR-Engagement Dimensions

EHR-Engagement Dimension code	Description
EHR-E.A	Closed (EHR is a professional-only space, not shared with, or accessed by, the subject of care otherwise than through exercising legal access rights)
EHR-E.B	“Invited” data entry (e.g. patient permitted to enter nominated home monitoring data into a shared EHR space, but nothing else); no import to/from a PHR
EHR-E.C	Personal health space offered to the subject of care, which may be shared with clinicians (but no link to the clinicians’ EHR)
EHR-E.D	Read-only access to the EHR; any errors or disagreements over content are to be communicated to a nominated party, no changes can be made directly to the EHR
EHR-E.E	Freedom to contribute to all parts of the EHR (e.g. to contribute or annotate goals in a care plan written by others, correct errors or comment on disagreements)
EHR-E.F	Explicit (pre-agreed) entries may be sent from the PHR to the EHR
EHR-E.G	Two-way seamless collaboration between the EHR and the PHR to support shared care

Annex A
(informative)

Published definitions of the PHR

A.1 Introduction to this annex

This report is a brief review of several published definitions of PHRs.

In many of the articles reviewed, the definition of PHR is that provided by the National Alliance for Health Information Technology (NAHIT), which describes the PHR as "*an electronic record of health related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared and controlled by the individual*".

Some of the other definitions below extend this basic definition by referring to some additional features or ideas. Each definition is preceded by the source or reference.

A.2 PHR definitions that include services

These definitions refer to services in addition to PHR information access. For example, the first one considers decision-support tools as part of the PHR; the second is less specific, including services and tools in general.

White Paper: Personal Health Records — Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption

Tang, P.C., Ash, J.S., Bates, D.W., Overhage, J.M., Sands, D.Z.

J. Am. Med. Inform. Assoc. 2006; 13:121–126. DOI 10.1197/jamia.M2025

"*PHR systems capture health data entered by individuals and provide information related to the care of those individuals. Personal health records include tools to help individuals take a more active role in their own health. In part, PHRs represent a repository for patient data, but PHR systems can also include decision-support capabilities that can assist patients in managing chronic conditions.*"

Informatics: Electronic personal health records — Nursing's Role

Thede, L.

OJIN: The Online Journal of Issues in Nursing 2008; vol. 14 No. 1. DOI:10.3912/OJIN.Vol14No1InfoCol01

"*When PHRs were first conceptualized, the goal was to provide consumers with a view of their medical record. This goal has now expanded to providing both a view of one's medical record and also services and tools that make the PHR useful in promoting a healthy lifestyle.*"

A.3 PHR definitions that specify technology

Viewpoint Paper: Governance for Personal Health Records

Recti, S.R., Feldman, H.J., Safran, C.

J. Am. Med. Inform. Assoc. 2009; 16:14–17. DOI 10.1197/jamia.M2854

"*Electronic personal health records are software applications that patients can use as 'communication hubs', to access and use information from their medical records and other sources. While the specific definition of a personal health record (PHR) is still evolving, the underlying concepts supporting patient involvement and* *shared medical records date back to the 1970s, and studies indicate that sharing the record tends to improve communication between doctor and patients.*"

Information Gap: Can health insurer personal health records meet patients' and physicians' needs?

Grossman, J.M. and others

Health Aff March 2009, vol. 28 No. 2 377-389. DOI: 10.1377/hlthaff.28.2.377

"*A PHR is a centralized place for people to electronically store and organize their personal health information, separate from electronic or paper medical records maintained by their health care providers. Many envision patients' control over PHR content and access, portability, and the capability to maintain a lifelong patient history as essential components of a valuable PHR.*"

A.4 PHR definitions that focus on the role of the patient

These consider the patient's role (and the roles of others) in PHR management. The consideration of privacy and security, and the control by the patient (carer or tutor) over the information about his or her health is a common consideration in many of these definitions.

What it takes: characteristics of the ideal personal health record

Kahn, J.S. and others

Health Aff. March 2009, vol. 28 No. 2 369-376. DOI: 10.1377/hlthaff.28.2.369

"*A PHR is a tool to use in sharing health information, increasing health understanding, and helping transform patients into better-educated consumers of healthcare.*"

Implementation of personal health records by case managers in a VAMC general-medicine clinic

Tobacmana, J.K., Kissinger, P., Wells, M., Prokuski, J., Hoyer, M., McPherson, P., Wheeler, J., Kron-Chalupa, J., Parsons, C., Weller, P., Zimmerman, B.

Patient Education and Counseling July 2004; 54(1):27-33. DOI: 10.1016/S0738-3991(03)00184-8

"*The PHR can be regarded as a "low-tech alternative" to electronic medical records, for it is designed to facilitate easy access to vital medical information by patients.*"

Building a personal health record from a nursing perspective

Lee, M., Delaney, C., Moorhead, S.

IJMI 76s(2007) s308-s316. DOI: 10.1016/j.ijmedinf.2007.05.010

"*PHR is described as a form of EHR; however, in essence, it is managed and controlled by patients (individuals) rather than by healthcare providers. While there is no uniform definition for PHR, the concept includes an electronic application enabling individuals to access and manage their own lifelong health information and to share all or parts of such information with authorized persons in a secure and confidential environment. Thus, a PHR is comprised of an aggregate of all the health care experiences of an individual.*"

AHIMA e-HIM® Workgroup

"*The personal health record (PHR) is an electronic, 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 does not replace the legal record of any provider.*"

myPHR by AHIMA

"*The PHR is a tool that you can use to collect, track and share past and current information about your health or the health of someone in your care. Sometimes this information can save you the money and inconvenience* *of repeating routine medical tests. Even when routine procedures do need to be repeated, your PHR can give medical care providers more insight into your personal health story.…*

Important points to know about a Personal Health Record:

- *You should always have access to your complete health information.*
- *Information in your PHR should be accurate, reliable, and complete.*
- *You should have control over how your health information is accessed, used, and disclosed.*
- *A PHR may be separate from and does not normally replace the legal medical record of any provider.*

Medical records and your personal health record (PHR) are not the same thing. Medical records contain information about your health compiled and maintained by each of your healthcare providers. A PHR is information about your health compiled and maintained by you. The difference is in how you use your PHR to improve the quality of your healthcare."

Health Record Banking: A Practical Approach to the National Health Information Infrastructure

Yasnoff on eHealth (Archive for June, 2006)

http://williamyasnoff.com/?m=200606 from http://www.healthbanking.org/index2.html

"*Each person keeps an up-to-date copy of their lifetime health record in an 'account' with a 'health record bank'. All access to the information in the account is controlled by the account-holder (the consumer), who makes the information available to health care providers whenever necessary. Each consumer may also access their own record as needed.*"

Health Record Banks themselves would be non-profit organizations required to follow stringent privacy and confidentiality practices to protect the information (either via open and transparent community oversight or legally mandated government regulation).

Global Definitions of EHR, PHR, E-Prescribing and Other Terms for Healthcare Organizations

Rishel, W., Handler, T.

Gartner (December 2008)

"*A PHR is a patient-owned and patient-controlled online record of medical information that is interoperable with other sources of personal health information about a patient. To meet our definition, these statements about a PHR must all be true:*

- *The patient owns his/her personal health information.*
- *The patient has the authority to populate, depopulate, annotate or share the information contained therein.*
- *When authorized by the patient, the PHR may be populated from a variety of sources, including, but not limited to:*
  - *The patient directly*
  - *Healthcare providers and wellness organizations such as gyms*
  - *Healthcare payers, including claim information and other information received by payers from other contracted or noncontracted medical care providers*
  - *The authority of the patient may be assumed by the parent of a minor or another designee subject to legal requirements.*"

In the definition below, the term Personally Controlled Health Records is introduced to underscore that it is the patient that is in control. The PCHR is in fact the conjunction of the PHR and distributed EHR ideas: the patient is poised to take control of his/her personal medical information that can be fragmented across multiple treatment sites. In this paper, the role of parents, tutors and relatives is also considered (because it is centred on a PHR for children and adolescent patients).

Whose Personal Control? Creating Private, Personally Controlled Health Records for Pediatric and Adolescent Patients

Bourgeois, F.C., Taylor, P.L., Emans, J., Nigrin, D.J., Mandl, K.D.

JAMIA 2008; 15:737-743 doi:10.1197/jamia.M2865

http://www.jamia.org/cgi/content/abstract/15/6/737

"*Personally controlled health records (PCHRs), a subset of personal health records (PHRs), enable individuals to aggregate, securely store, and access electronic health information from multiple sites of care, and to share that information with care providers and others." Providing "…shared, ubiquitous, consent-modulated access to personal medical information.*"

A similar concept can be found at: http://indivohealth.org/

The next definition underlines the interest in a ubiquitous access.

Mayo Clinic Web Site

http://www.mayoclinic.com/health/personal-health-record/MY00665

"*A personal health record is simply a collection of information about your health. If you have a shot record or a box of medical papers, you already have a basic personal health record. And you've probably encountered the big drawback of paper records: You rarely have them with you when you need them.*

Electronic personal health record systems — often called PHR systems — remedy that problem by making your personal health record accessible to you anytime via a Web-enabled device, such as your computer, phone or PDA.

Personal health records are not the same as electronic health records (EHR) or electronic medical records (EMR), which are owned and operated by doctors' offices, hospitals or health insurance plans. Unfortunately, not many doctors' offices use these systems yet and those that do often limit your access to and control of your medical record."

A.5 PHR characterizations

The following extract is not a definition but a list of properties that characterize the PHR.

The National Committee on Vital and Health Statistics

http://www.ncvhs.hhs.gov/050909lt.htm

"*In practice, PHRs and PHR systems are currently very heterogeneous. NCVHS concluded that it is not possible, or even desirable, to attempt a unitary definition at this time. However, the Committee believes it is possible to characterize them by their attributes: the scope or nature of their information/contents, the source of their information, the features and functions they offer, the custodian of the record, the storage location of the content, the technical approach to security, and the party who authorizes access to the information. Some of the approaches to each of these attributes, as heard by the Committee, are listed below.*

- *Scope and nature of content*
  - *Some PHR systems do not contain any patient clinical data, but just have consumer health information, personal health journals, or information about benefits and/or providers.*