PD ISO/TR 14292:2012

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

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National foreword

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The UK participation in its preparation was entrusted to Technical Committee IST/35, Health informatics.

A list of organizations represented on this committee can be obtained on request to its secretary.

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ISBN 978 0 580 73744 2

ICS 35.240.80

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This Published Document was published under the authority of the Standards Policy and Strategy Committee on 30 April 2012.

Amendments issued since publication

Date	Text affected

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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)

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Foreword

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

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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.

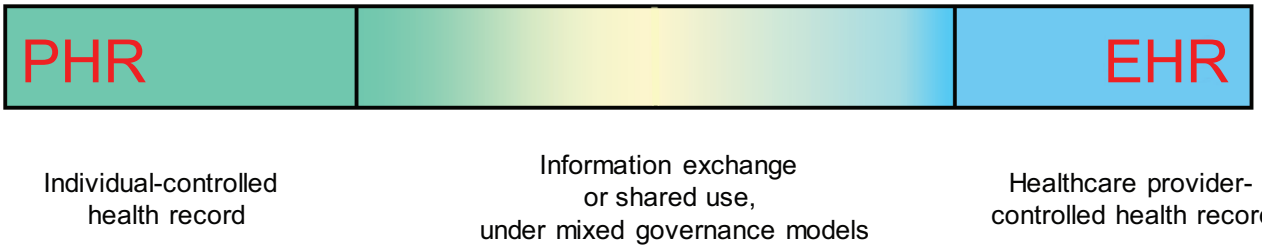

Figure 1 — The PHR-EHR spectrum

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.

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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.

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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]

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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

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