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Health informatics — Person-owned document repository for PHR applications and health information exchange

Informatique de santé — Dépôt de documents personnels pour les applications PHR et échange d'informations sur la santé

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Foreword

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For an explanation on the voluntary nature of standards, the meaning of ISO specific terms and expressions related to conformity assessment, as well as information about ISO's adherence to the WTO principles in the Technical Barriers to Trade (TBT) see the following URL: Foreword - Supplementary information

This document was prepared by ISO/TC 215, *Health informatics*.

Health informatics — Person-owned document repository for PHR applications and health information exchange

1 Scope

This document describes the concept of a person-owned repository (PoR) of health documents. It suggests representative uses for PoRs and surveys some of the existing technologies and projects that can be categorized as PoRs. It is, however, not intended to cover document formats (such as HL7 CDA), exact communication protocols, details of security and privacy protection strategies, or any other normative aspects of PoRs.

2 Normative references

There are no normative references in this document.

3 Terms and definitions

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

ISO and IEC maintain terminological databases for use in standardization at the following addresses:

— ISO Online browsing platform: available at http://www.iso.org/obp

— IEC Electropedia: available at http://www.electropedia.org

3.1
access control
means of ensuring that the resources of a data processing system can be accessed only by authorized entities in authorized ways

[SOURCE: ISO/TS 21547:2010, 3.2.1]

3.2
authorization
granting privileges

[SOURCE: ISO/TR 14292:2012, 2.4]

3.3
clinical information
information about a person, relevant to his or her health or healthcare

[SOURCE: ISO 13606-1:2008, 3.13]

3.4
data owner
person having responsibility and authority for the data

[SOURCE: ISO/TR 14292:2012, 2.10]

3.5
electronic health record
EHR
information relevant to the wellness, health and healthcare of an individual, in computer-processable form and represented according to a standardized information model

[SOURCE: ISO 18308:2011, 3.20]

3.6
healthcare
activities, services or supplies related to the health of an individual

[SOURCE: ISO/TR 12773-2:2009, 2.15]

3.7
healthcare provider
healthcare organization or healthcare professional involved in the direct provision of healthcare

[SOURCE: ISO 18308:2011, 3.32]

3.8
information broker
person or system that commercially undertakes to locate, to retrieve and to provide information

3.9
personal health record
PHR
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

Note 1 to entry: See ISO/TR 14292:2012, 4.1.

3.10
service
ability of a system to provide a defined set of output information based on a defined set of input information

[SOURCE: ISO/TR 14292:2012, 2.31]

4 Symbols and abbreviated terms

AA	authentication agent
CDA	clinical document architecture
CRIB	clinical research information broker
CRIC	clinical research information consumer
CRIP	clinical research information provider
EHR	electronic health record
HIE	health information exchange

PHM personal health management

PHR personal health record

PoR person-owned repository (of health documents)

5 Characterization of PoR technologies

5.1 Introduction

A PoR is a repository of health-related information about an individual which is owned, managed, accessed and shared by the individual using computer technology. A PoR can be implemented in many different ways such as on a mobile device, USB, personal computer, or by using a PHR application or server-based cloud service[1][2]. Its basic purpose is to enable a person to collect and share their health information. Potential sources of information include clinical information from healthcare providers, results from laboratories, health status data such as vital signs from personal sensor devices, and any health-related information entered by the individual who owns the PoR. Once collected, the information stored in the PoR will be available for sharing with other parties as determined by the individual that owns the PoR.

A PoR is substantially different from health document repositories operated by healthcare providers or provider-sponsored HIEs which primarily support the collection of patient health information for exchange among healthcare providers (although patients may have some access via a portal). While such provider-centric HIEs are beneficial in many ways, there are circumstances where HIEs may not be adequate for reasons including lack of budget, lack of motivation for information sharing among providers, regulatory barriers, and poor support from individuals and patients. In those cases, the PoR concept can be an effective alternative to provider-centric HIEs.

The defining characteristic of a PoR that distinguishes it from other types of health document repositories is that the individual has total control over every aspect of their health information within a PoR, including the technology used to implement the PoR, when and how information is collected, what information is retained and to whom it is provided.

One of the biggest concerns with PoRs could be data reliability. Information sharing in HIE is thought to be conducted between trustworthy participants (providers, public health authorities, etc.), but the fact that each owner of a PoR has total control over how it is used may pose a negative effect on the reliability of data from the PoR. As such, there is a strong need for means to guarantee the reliability of PoR-sourced health data and one solution to this problem can be PKI-based digital signatures[3].

5.2 Considerations for the PoR implementation

5.2.1 General

A PoR may be owned and controlled by an individual using applications and technology selected by the individual; however, consideration needs to be given to the possible means by which PoRs will interoperate with EHR systems and other repositories of patient-related information maintained by networks of healthcare providers. This consideration needs to take into account:

a) the health IT systems and infrastructure and related health informatics standards that may be applicable to the exchange of patient health information at the level of any particular region, nation, province/state or healthcare provider network;

b) the need to support trusted flows of information from provider-owned repositories to individuals' PoRs[4];

c) the desirability of supporting flows of information from individuals' PoRs into provider-owned repositories;

d) the level of control for documents from healthcare professionals;

e) privacy and security issues, including the ways in which an individual's health information may be used and who may access it after it has been provided to a potential user.

Existing repositories of patient healthcare information often hold and/or require the exchange of information as CDA documents.[5] It has therefore been assumed that PoRs should have the capability to handle clinical information in the form of documents (CDA documents and/or other document types). Nevertheless, consideration also needs to be given to the other forms in which information may be interchanged and the applicable standards needed to support such interchanges.

5.2.2 Classification criteria of PoR implementations

5.2.2.1 General

PoR implementations can be classified by the combination of two criteria: the storage type and the document discovery mechanism.

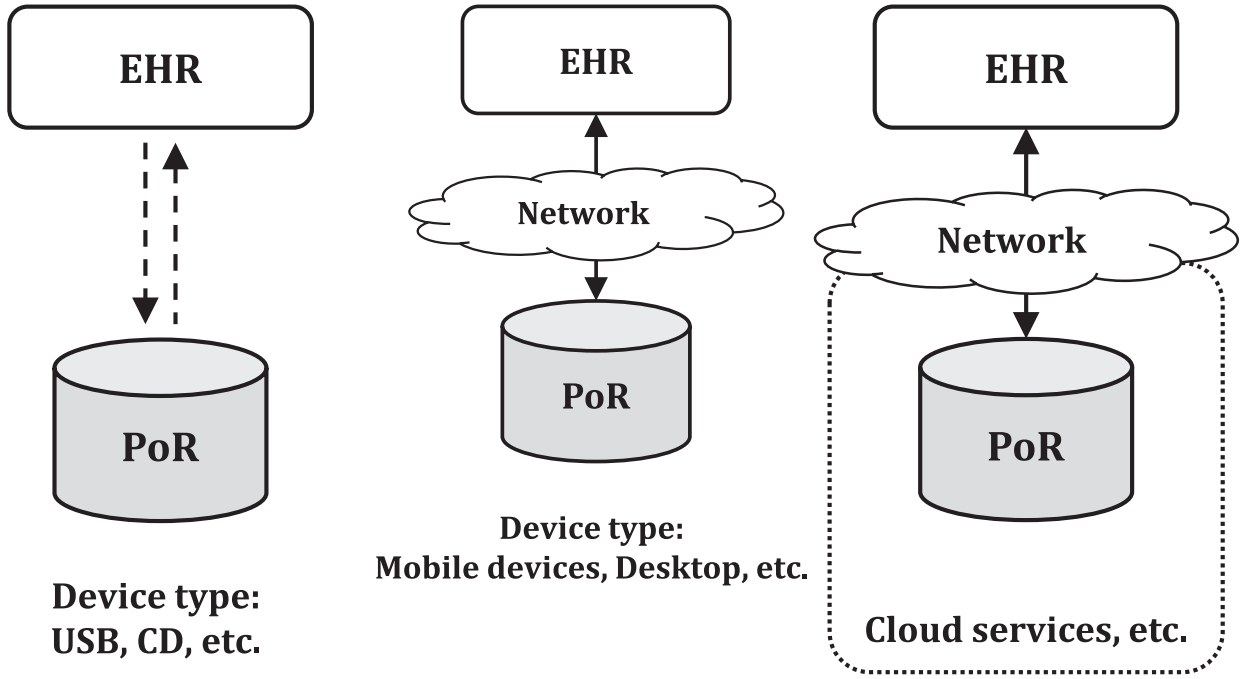
5.2.2.2 Storage type

The storage type refers to the way health documents are stored and managed and three storage types are considered in this document (Figure 1).

— Off-line personal storage: this type of storage includes USB dongles, CDs, personal devices with USB or similar connection, etc. with or without built-in applications.

— Network connected personal device: personal digital devices with wired or wireless network connectivity and relevant applications including smart phones, tablets, laptops, and desktop computers that are not shared with others fall into this type.

— Network connected shared storage service: the most common form of this storage type is cloud-based storage services.



a) Off-line personal storage b) Network connected personal device c) Network connected shared storage device

Figure 1 — Storage type of PoR

5.2.2.3 Document discovery mechanism

The document discovery mechanism refers to the way a health document consumer can find a particular document. The following cases are considered in this document:

— manual discovery: only simplistic searching and browsing is provided;

— registry/index service: various types of remote queries based on the document metadata are facilitated and offered through a network.

6 Potential uses for PoRs

6.1 Clinical document exchange using PoRs

Clinical document exchange between healthcare providers is not always feasible for reasons including lack of budget, lack of motivation for information sharing among providers, regulatory barriers, and poor support from individuals and patients. Alternatively, individuals can participate in this process to facilitate clinical document exchange using PoRs (Figure 2). This could be possible because patients and other qualified individuals can request their own medical records from healthcare providers in most jurisdictions. Individuals can receive their clinical documents from healthcare providers and store them in their PoRs. Conversely, they can send their documents in PoRs to other healthcare providers or other parties, as needed. In the latter case, de-identification may be applied, depending on the purposes such as research.