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# OmniPHR: A distributed architecture model to integrate personal health records

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ABSTRACT

The advances in the Information and Communications Technology (ICT) brought many benefits to the healthcare area, specially to digital storage of patients' health records. However, it is still a challenge to have a unified viewpoint of patients' health history, because typically health data is scattered among different health organizations. Furthermore, there are several standards for these records, some of them open and others proprietary. Usually health records are stored in databases within health organizations and rarely have external access. This situation applies mainly to cases where patients' data are maintained by healthcare providers, known as EHRs (Electronic Health Records). In case of PHRs (Personal Health Records), in which patients by definition can manage their health records, they usually have no control over their data stored in healthcare providers' databases. Thereby, we envision two main challenges regarding PHR context: first, how patients could have a unified view of their scattered health records, and second, how healthcare providers can access up-to-date data regarding their patients, even though changes occurred elsewhere. For addressing these issues, this work proposes a model named OmniPHR, a distributed model to integrate PHRs, for patients and healthcare providers use. The scientific contribution is to propose an architecture model to support a distributed PHR, where patients can maintain their health history in an unified viewpoint, from any device anywhere. Likewise, for healthcare providers, the possibility of having their patients data interconnected among health organizations. The evaluation demonstrates the feasibility of the model in maintaining health records distributed in an architecture model that promotes a unified view of PHR with elasticity and scalability of the solution.


## 1. Introduction

The Health Information Technology (HIT) has evolved greatly, but even now we generally have not our entire patient health history in an unified viewpoint. We still have different health records with assorted healthcare providers (i.e. healthcare professionals and healthcare organizations) that we interacted lifelong [1,2]. At every medical appointment, patients must tell their whole health history again, losing time and accuracy. In addition, there are technical issues with health records, since there are several health data standards for different purposes, as can be seen in Table 1. The standards are intended to systematize the patients' clinical datasets and define protocols to make the health information uniform. These are usually dedicated to standardize the storage and to regulate the clinical and demographic data about patients. Health records typically incorporates data regarding vital signs, laboratory exams results, evolution and diagnosis. However, in some cases, the standards are guidelines designed to address health records in some regions or countries, such as standards CEN [3] in Europe or xDT in Germany [4]. Patient's health data are collected throughout life and can receive data from several sources, including health professionals records from laboratories, clinics or hospitals, including data from sensors that monitor the patient's health [5,6].

Electronic Health Record (EHR) is a standardized information model, enabling integration among multiple healthcare providers, and this integration is considered their main advantage [24,25]. EHR has several benefits, ranging from supporting medical prescriptions [26], improving disease management [27] and contributing in the reduction of severe medication errors [28]. However, EHR has limitations regarding interoperability, e.g when health organizations adopt international but heterogeneous standards [29]. Other limitations are related to security of data exchanged between health organizations, or to non-incorporation of data about patient's wellness, such as sports activities or eating habits [26].

PHR (Personal Health Record) has some advantages over EHR, since PHR can receive data entered by patient [30]. For instance,

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**Table 1**
Standards for health records storage and communication.

| Acronym | Ref. | Short description |
|---|---|---|
| ASC X12N | [7] | Accredited Standards Committee X12N |
| CCR | [8] | Continuity of Care Record |
| CEN/TC 251 | [9] | European Committee for Standardization |
| DICOM | [10,11] | Digital Imaging and Communic. in Medicine |
| HL7/CDA/FHIR | [12,13] | Health Level-7/ Fast Health. Interop. Res. |
| HIPAA | [14] | Health Insur. Portab. and Account. Act |
| ICD/ICF/ICHI | [15] | Family of International Classifications |
| ICPC | [16] | International Classification of Primary Care |
| IHE | [17] | Integrating the Healthcare Enterprise |
| ISO/TC 215 | [18] | International Organization for Standard |
| LOINC | [19,20] | Logical Observ. Identif. Names and Codes |
| *open*EHR | [21] | Open Electronic Health Records |
| SNOMED-CT | [22,23] | Systematized Nomenclature Of Medicine |
| xDT | [4] | Germany Family of Data Exchange Formats |

the patient can inform weight or blood pressure readings [31]. However, PHR has some limitations and challenges [30]. The PHR issues range from usability (as usefulness, satisfaction and ease of use) [32]; low level of adoption (e.g. by patients with chronic medical conditions) [33]; few patients and physicians knowledge regarding PHR features; incompatibility or lack of integration with existing health systems; to concerns with security and access permissions for third-parties (e.g. physicians and family members) [34].

Considering these issues, our research goal is to answer how would be possible to have a single view of PHR in order to be distributed, up-to-date and interoperable to patients and healthcare providers use. The scientific contribution is to provide a distributed and interoperable architecture model for PHR which addresses a unified viewpoint for both patients and healthcare providers. Patients can take advantage of maintaining their health history in a single view, as well as healthcare providers have these data up-to-date, regardless of where the patient was treated. To answer the research question, we propose a model named OmniPHR, where the prefix 'Omni' comes from omnipresent, meaning that is present everywhere.

The remaining of article is organized as follows. Section 2 summarizes the main concepts, challenges and models that support the proposal. Section 3 explains the most significant related work. Section 4 presents the foundation technologies for model development. Section 5 details the architecture model. Section 6 presents the evaluation and methodology of study. Section 7 summarizes the results and discuss the impacts, limitations and future directions. Finally, Section 8 presents the conclusions of the work.

## 2. Background

According to ISO/TR 14639, EHR is "information relevant to the wellness, health and healthcare of an individual, in computer-processable form and represented according to a standardized information model" [24]. EHR refers to a structure in electronic way of patient's health records, collected and stored in a repository, that can be shared by different digital formats. EHR can contain several data groups, such as allergies, vital signs, medical appointments, laboratory exams results, medical imaging and diagnoses. To differentiate health records that are not integrated between healthcare providers, these are named EMRs (Electronic Medical Records). EMR can be considered a special type of EHR with specific focus into internal medical domain of health organizations [24,25].

Otherwise, according ISO/TR 14639, PHR refers to a "representation of information regarding, or relevant to, the health, including wellness, development and welfare of that individual" [24]. As patients are the owner of their health records, they can manage and grant permissions for access or share their health data with third-parties [24]. PHR is oriented to the patient but can be integrated with EHR [30]. Some healthcare providers have been successful in improving communication with patients using mobile technology (mPHR), where PHR allows patients self-monitoring and managing their health status [35]. PHR can receive data from healthcare providers, stored in a repository where patient has access [36].

### 2.1. Challenges facing the personal health records

There are many health systems that use databases in proprietary formats. These databases are structured to be accessed exclusively by those systems, with little or no interoperability with others [37]. Usually legacy systems in many health organizations preserve proprietary data structures. In general, these databases are hosted in a data center inside the health organizations, with restricted access to internal health professionals. In some cases, e.g. laboratory exams results, patients and healthcare providers can have external access to health records in a restricted manner, only to be viewed or printed. Another factor is that the health data is becoming increasingly larger. Several studies bring out crucial points as getting this mass data about patients health, such as standardization of data, storage capacity, location, safety and how to filter, analyze and quickly obtain such data [38]. Allied to these issues, health organizations maintain the patient's EHR indefinitely, even outdated. This is required for legal reasons, depending on the country [2].

In many cases healthcare providers do not share their patients' data. Hence, they do not have these data up-to-date when their patients are assisted by other healthcare providers [39]. Moreover, these records are usually stored in different standards on different health organizations, which brings difficulties for exchange health records between organizations [29]. To integrate health systems, there are several health standards for different purposes and initiatives to mitigate some integration problems [40].

Other problems arise from the potential existence of health records duplicated within the health organizations due to the ambiguity or repetition of some patient's names [41,37]. Furthermore, from the patients' viewpoint, they do not have an integrated view of their health records. Although there are consolidated standards to structure the patient's health data, the adoption and implementation of EHR, particularly PHR, is still a challenge [42]. Much of the obstacles come from the fact that health records are sensitive and have complex management for owners and users [43,44]. There are concerns in PHR adoption from healthcare providers and patients, because users are afraid to share their data, as there are concerns about where data will be stored and who will have access to it [45].

Other barriers include concerns from healthcare providers regarding to the management and validity of records registered in PHR, since patients are the owner and can manage their records [37]. In addition, because of the high cost of datacenters, many PHR services have migrated to third party providers using cloud computing architectures [43]. However, according Mxoli [46] "access management, security issues, legal issues and loss of data are some of the risks that negatively impact the storing of PHRs in the Cloud" [46].

### 2.2. Models for the personal health records

Our proposal is an architecture model for PHR based on a distributed P2P (Peer-to-peer) network system. With the purpose of analyzing related work to compare with our proposal, we look for the main models mentioned in the literature. According to