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Evaluation of personal health record systems through the lenses of EC research projects

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ABSTRACT

Personal health record (PHR) systems are a rapidly expanding area in the field of health information technology which motivates an ongoing research towards their evaluation in several different aspects. In this direction, we present a systematic review of the currently available PHR systems. Initially, we define a clear and concise set of requirements for efficient PHR systems which is based on real-world implementation experiences of several European research projects and also on established and widely used formal standards. Subsequently, these requirements are used to perform a systematic evaluation of existing PHR system implementations. Our evaluation study provides a thorough requirement analysis and an insight on the current status of personal health record systems. The results of the present work can therefore be used as a basis for future evaluation studies which should be conducted periodically as technology evolves and requirements are revised.

1. Introduction

The advancements in healthcare practice, the limitations of the traditional healthcare processes and the need for flexible access to health information, create a continuing demand for electronic health systems (e-health systems) [1,2] everywhere. In this direction, personal health record (PHR) systems are a new, innovative and constantly evolving area that empowers patients to take more active role in their own health and make informed decisions. A PHR system's primary goal is to provide the patient with the ability to maintain and manage his personal health record, i.e. "*the systematic collection of information about an individual's health and health care, stored in electronic format*" [3,4].

The PHR concept is patient centric in the sense that the management of a personal health record is primarily the responsibility of the patient. PHRs provide a complete summary of patients' health history, enhance accurate clinical diagnosis and empower patients in their own self health management. The potential of personal health records to improve healthcare delivery and reduce costs has been recognized in many countries worldwide [5,6]. At the same time PHR research, development and adoption efforts have received significant funding.

The value of personal health record systems is expected to increase by the new wave of telemedicine applications [7], as part of the broader context of personalized medicine [8] which provides an unprecedented way to empower the healthcare process. Given the growing number of such applications and services offered, personal health records are expected to play a critical role as an invaluable source of information from the patient's perspective which will assist the clinicians to make more accurate diagnoses and empower patients to make informed decisions.

Due to this global interest and support of personal health records, emerging PHR systems and their associated tools are evolving constantly, which in turn led to numerous evaluation studies focusing on their functionality and usability [9–20]. Although there is a significant body of published research results on evaluating the functionality and usability of PHR systems, it is also evident that "…*more research is also needed that addresses the current lack of understanding the optimal functionality and usability of these systems, and how they can play a beneficial role in supporting self-managed healthcare*." [21].

In this direction, this paper focuses on defining a clear and concise set of requirements for efficient personal health record systems. The performed requirement analysis performed follows both a top-down and a bottom-up approach, i.e. it is based on the study of well-established high level functionality standards on the one hand, and challenges that have been identified in several research projects funded by the European Union in the context of the 7th Framework Programme (FP7) which focus on the

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innovative exploitation of PHR systems, on the other hand. Thus, the specified set of requirements constitutes a composite evaluation model which is subsequently used to compare numerous PHR systems implementations. The requirements are interpreted as comparison criteria in the evaluation process of the PHR systems. The results of this comparative evaluation study indicate the systems most suitable for adoption or functional extension in order to satisfy the various needs of healthcare environments.

As a result the contribution of this research is twofold. The study provides a simplified yet elaborate evaluation model for PHR systems, which is based on thorough requirement analysis, as well as an insight on the current status of personal health record systems in terms of functionality, architecture and other technological characteristics.

The rest of this paper is organized as follows: The rest of Section 1 presents the motivating scenarios that were used for the elicitation of the PHR system evaluation criteria. Section 2 presents the methodology of the evaluation process. This section describes in detail the selection process of the evaluated PHR systems and the formulation of the evaluation criteria through various research project scenarios and well-established high level standards. Section 3 applies the evaluation model in the analysis and comparison of the selected PHR systems and presents the results of this process. Section 4 discusses the aforementioned results against existing literature while Section 5 concludes the paper.

1.1. Motivating scenarios from EC research projects

In this section we describe the motivation scenarios from the three EU-funded research projects, namely the p-medicine, the eHealthMonitor and the EURECA projects that served as raw material in the formulation of our evaluation model.

The p-medicine EU project (http://www.p-medicine.eu/) aspires to create an infrastructure that will facilitate the translation from current medical practice to personalized medicine. Essential to the realization of personalized medicine is the development of information systems capable of providing accurate and timely information about potentially complex relationships between individual patients, drugs, and tailored therapeutic options [22]. In the context of this project, a range of Interactive Empowerment Service (IEmS) [23,24] are being designed and developed, many of which demand the presence and use of a PHR system. One of these services is the patient profiling which collects information using different intelligent techniques and combines them to construct patient profiles which are subsequently utilized for intelligent decision making and personalized doctor–patient interactions.

The eHealthMonitor project (http://www.ehealthmonitor.eu/) provides a platform that generates a Personal eHealth Knowledge Space (PeKS) as an aggregation of all relevant sources (e.g., EHR and PHR) relevant for the provision of individualized personal eHealth Services. eHealthMonitor develops an adaptive platform architecture for individualized personal electronic healthcare services. This serves as a basis for personal eHealth services that support cooperation and decision making of the involved participants (patients, clinicians, social services) through web, mobile and remote access channels. Key requirements for the PHR subsystem in this project is to be (a) able to implement intelligent alerts, (b) linked with external monitoring services (environmental and biomedical) and (c) capable of creating short and understandable summaries for large junks of information. Adaptability according to patient profile is a necessity in this project as well.

EURECA (http://eurecaproject.eu/) is developing an advanced, standards-based and scalable semantic integration environment enabling seamless, secure and consistent bi-directional linking of clinical research and clinical care systems. Achieving semantic interoperability among EHR, PHR and Clinical Trial systems is at the core of EURECA project. The use of supported terminological standards, such as SNOMED CT, ICD-10 and LOINC, will facilitate in the future easy linkage to clinical information systems adhering to those standards. Obviously this project's requirements dictate the use of a PHR system that exploits widely used terminology standards and provides mechanisms for easily exporting and importing data.

Although all three EU-projects rely in one form or another on a PHR system and may have overlapping goals, in essence they have different requirements. For example, p-Medicine relies on patient profiling and intelligent recommendation services, whereas the eHealthMonitor focuses on real life monitoring services, intelligent alerts and summaries. On the other hand the service scenarios envisaged in EURECA imply interoperability between systems, data sharing mechanisms and strong use of terminology standards such as SNOMED CT, LOINC and ICD-10. Under the prism of those implementation approaches which served as motivation for our study, we proceed further to establish the concrete evaluation criteria for PHR systems.

2. Methodology

In this section we describe the methodology followed in this study in order to establish the evaluation criteria. Firstly, we describe the process of selecting the candidate PHR systems for this review. Then, we argue about the selected PHR system requirements which formulate our evaluation model.

2.1. Identification of candidate PHR systems

Several PHR systems implementations are described in the literature and most of the efforts come from the industry. An indicative recent study reports 91 different PHR commercial products in use by firms, institutions, or governments [25]. Within such a context, the systematic documentation of available systems and their evaluation with respect to specific functional and operational aspects is of importance. This is the purpose of the work presented in this manuscript. The methodological framework for our systematic attempt to identify available solutions and their capabilities are presented in the subsequent sections.

2.1.1. Search

A thorough search of the web for PHR systems and literature for relevant papers was mandatory for the review. For the web sites search we used the Google search engine (www.google.com) using specific terms. Our strategy required that the string "PHR" or one of the phrases "personal health record", "personal healthcare record", "patient health record", "patient healthcare record" appeared in the introduction or the description of the web page along with the term "system" or "application" or "tool". Publications' search related to PHRs was conducted using specialized search engines for publications such as Google Scholar,[1] Embase,[2] PubMed[3] and PLOS Medicine[4] as well as web sites from individual journals. Initially we narrowed the search to web pages and publications which are written in English. Our search at the first step identified 113 records. Screening excluded 74 records as irrelevant to the topic or identified as duplicates. The remaining 39 web site descriptions and full-text articles were retrieved for additional scrutiny, of which 9 proved irrelevant or describing systems that are obsolete such as Google Health (www.google.

[1] http://scholar.google.com.
[2] http://www.embase.com/.
[3] http://www.ncbi.nlm.nih.gov/pubmed.
[4] http://www.plosmedicine.org/.

com/health/) and 5 were identified as duplicates. The flow of search methodology is depicted in Fig. 1.

2.1.2. Selected systems

Following the above methodological approach, we have identified the commonly used PHR systems that appear in Table 1.

Having selected the candidate personal health record systems, we proceeded further to the elicitation of the PHR system requirements. The requirement analysis is based on relevant well-established PHR standards and also on the motivating scenarios briefly outlined in Section 1.1, from the three EU-funded research projects that our group is part off. Those scenarios are relying in one form or another in PHR systems and show the diversity in the requirements of such systems. After the analysis of the selected service scenarios and the thorough study of the PHR standards we established the evaluation criteria that formulate our composite evaluation model which we subsequently applied for our comparative evaluation of the candidate personal health record systems.

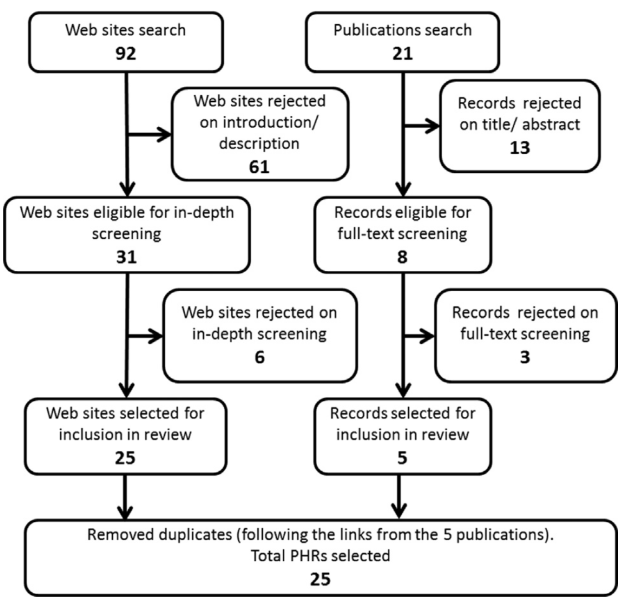

Fig. 1. Flow of search methodology.

Table 1
Candidate personal health record systems.

PHR system	URL
1. Microsoft HealthVault	http://www.microsoft.com/en-gb/healthvault/default.aspx
2. Web MD Health Manager	http://www.webmd.com/health-manager
3. NoMoreClipboard	http://www.nomoreclipboard.com/
4. PatientsLikeMe	http://www.patientslikeme.com/
5. Patient Ally	https://www.patientally.com/Main
6. Patient Fusion	http://www.practicefusion.com/pages/phr.html
7. MyOscar	http://myoscar.org/
8. myMediConnect PHR	http://www.passportmd.com/
9. eclinicalWorks Patient Portal	http://www.eclinicalworks.com/products-patient-portal.htm
10. MedHelp PHR	http://www.medhelp.org/
11. MyALERT	http://www.alert-online.com/myalert
12. CareZone PHR	https://carezone.com/
13. Indivo-X	http://indivohealth.org/
14. Epic MyChart	http://www.epic.com/software-phr.php
15. 911 Medical ID	http://www.911medicalid.com/
16. zweena PHR	http://www.zweenahealth.com/
17. MedicAlert	http://www.medicalert.org/
18. Tolven	http://www.tolven.org/
19. HealtheTracks	http://www.healthetracks.com/
20. LifeLedger	http://www.elderissues.com/
21. OpenMRS	http://openmrs.org/
22. KIS PHR	http://kismedicalrecords.com/
23. MedicKey PHR	http://medickey.com/
24. Dossia	http://www.dossia.org/
25. Minerva Health Manager	http://www.myminerva.com/

2.2. Establishing the evaluation criteria

In this section we analyze the basic requirements for a powerful, customizable and extendable personal health record system which are derived through the study of European research projects and PHR systems functional models developed by official standard development organizations (SDOs) [26].

2.2.1. The FOSS requirement

The use of electronic health record systems is facilitated by the free and open source software (FOSS). The free (license) concept intends to free users from any restrictions of proprietary software such as cost and distribution limitations. The users have extensive rights to study, copy and redistribute the software according to their discretion. On the other hand, the open source concept aims to provide them with the ability to modify the software according to their needs. They are able to access the source code of the software in order to understand the provided solution and possibly customize or extend it.

Apart from the obvious benefits of FOSS solutions, there are numerous other advantages. First of all, the fact that the source code is available to the public makes it possible to be tested widely and debugged quickly. FOSS solutions often provide better quality and technical support than enterprise solutions because of the worldwide community of developers and users that are involved. Moreover, the adoption of FOSS software eliminates the risk of enterprise tricks and conflicting interests that impose many restrictions to users. When FOSS is applied to the field of PHR systems, the resulting solutions guarantee personal health record systems with full access to the source code, reduced enterprise related risks, and free license to copy, distribute as well as change the software in order to meet healthcare specific domain requirements. For all these reasons, we consider the free and open source nature of a personal health record system as a basic requirement for its adoption.

2.2.2. The web-based system requirement

Another important requirement for a PHR system is its web based nature. A web based PHR system enables flexibility in usage and interoperability. Through web based PHR solutions, a user is able to access his personal health record, at any time and location, just by using an internet connection and a browser. So, the web based nature of a PHR system enhances accessibility and eliminates the need of downloading and installing software. Moreover, a web based PHR system is easily integrated with mobile communication devices, thus providing the ability to access the PHR not only through a computer but also through a smart phone or a tablet pc. Thus, web based PHR systems promote m-Health which is defined as “emerging mobile communication and network technologies to support healthcare” [27,28]. It is a new highly promising area that involves the exploitation of mobile devices to support healthcare delivery systems. m-health represents the evolution of e-health systems that has been achieved with the advances in mobile communication technology. An example m-health scenario is presented in Fig. 2. For all these reasons we

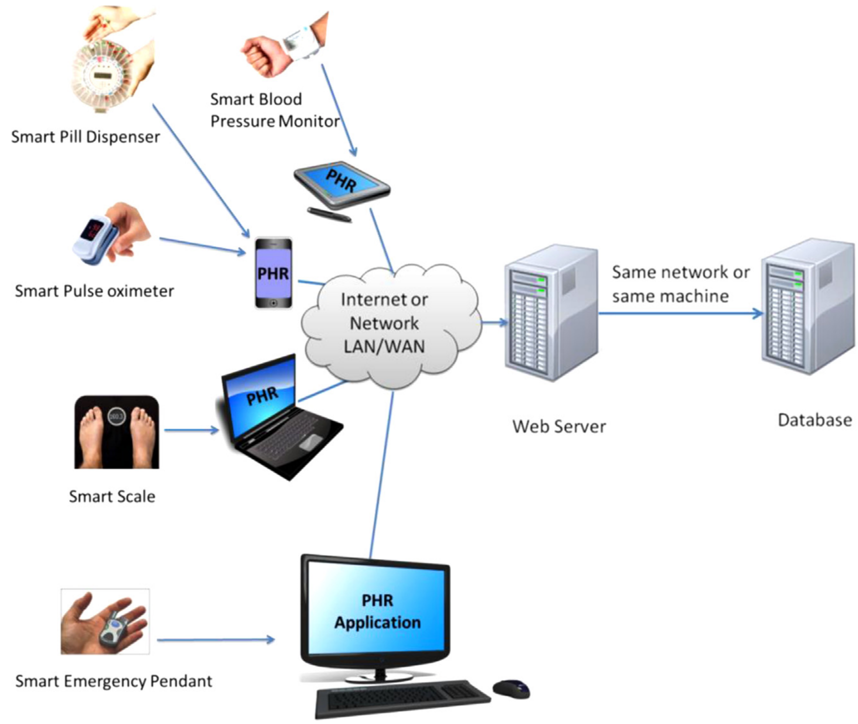

Fig. 2. An example of a m-health scenario.

consider the Web-based nature of a PHR system as a basic requirement for its adoption. In addition, we define the previous FOSS requirements combined with the Web-based requirement as W-FOSS requirements.

2.2.3. *Functionality requirements*

The requirements that we have described so far provide generic guidelines for the adoption of a PHR system which should be flexible, easily accessible, open to the community and free of proprietary software restrictions. Generally these requirements address the ease-of-use factor for the various categories of people that are involved in the product's lifecycle such as developers, product managers and consumers. Nevertheless, the selection of a powerful PHR system requires more detailed analysis in regard to functionality and security standards.

A PHR system needs to be in compliance with high quality standards, in order to be acknowledged as a high end product. In this direction, we have distinguished three significant efforts that attempt to address the need for functional specification and standardization in the constantly evolving area of PHR systems and generally electronic health record systems and we describe them briefly. The first is the International Organization for Standardization ISO/IEC 25000 series [29]. The second is the Personal Health Record System Functional Model that has been proposed by the Health Level Seven (HL7) organization (http://www.hl7.org/), while the third is the specification of Meaningful Use criteria that have been established by the U.S. Office of the National Coordinator for Health IT (ONC) (http://www.healthit.gov/).

The ISO/IEC 25000 standards series provides guidance for the use of the new series of International Standards named Software product Quality Requirements and Evaluation (SQUARE). SQUARE forms the base of the evaluation reference model and describes the general processes, activities and tasks that can be used to guide a software product quality evaluation. The product quality model (ISO/IEC 25040) categorizes system/software product quality properties into eight characteristics: functional suitability, performance efficiency, compatibility, usability, reliability, security, maintainability and portability. The product quality model can be applied to just any software product, or to a computer system that includes software, as most of the characteristics are general and relevant to both software and systems. The quality in use model (ISO/IEC 25010) defines five characteristics related to outcomes of interaction with a system: effectiveness, efficiency, satisfaction, freedom from risk, and context coverage. The quality in use of a system characterizes the impact that the product (system or software product) has on stakeholders. All these factors contribute to the quality in the use of the system.

The HL7 PHR System Functional Model (PHR-S FM) specifies a set of functions and security related features that PHR systems are required to, should, or may, support in order to be effective. An overview of the PHR-S FM is provided in Fig. 3.

Meaningful Use refers to a set of fifteen criteria that healthcare providers must meet in order to prove that they are using their EHR system as an effective tool in their practice. The core set of the necessary criteria and the menu with the optional criteria are presented in Fig. 4. All criteria are EMR related and the red highlighted criteria are also PHR related.

An ideal personal health record system should be fully or at least partially certified against high level functional standards, such as those described earlier, in order to be widely accepted as a high end product. Based on the study of functional standards and the research conducted in the three European projects and we have distinguished five function categories.

The first category is called Problem, Diagnosis and Treatment (PDT) Basic and encompasses related functions. In this category are included functions that provide the following services:

- Recording of a patient problem or an incident.
- Recording of the diagnosis process related data such as diagnostic tests (laboratory tests etc.), diagnostic procedures (surgeries etc.), diagnostic material (allergies, demographic elements, family history, immunizations, other diagnostic documents etc.) and diagnosis results.

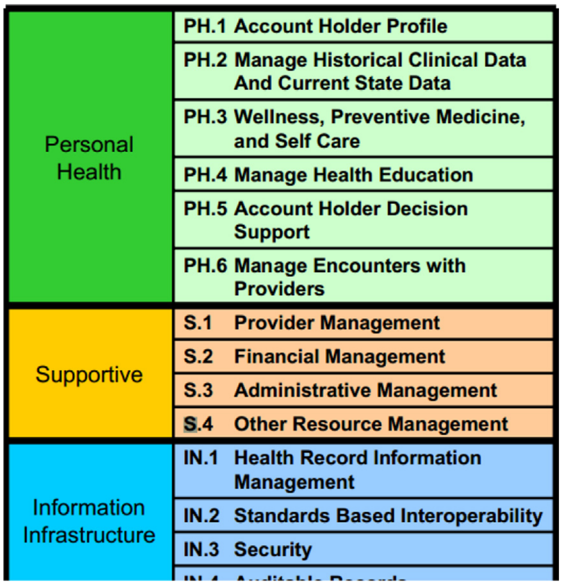

Fig. 3. HL7 PHR system functional model overview.

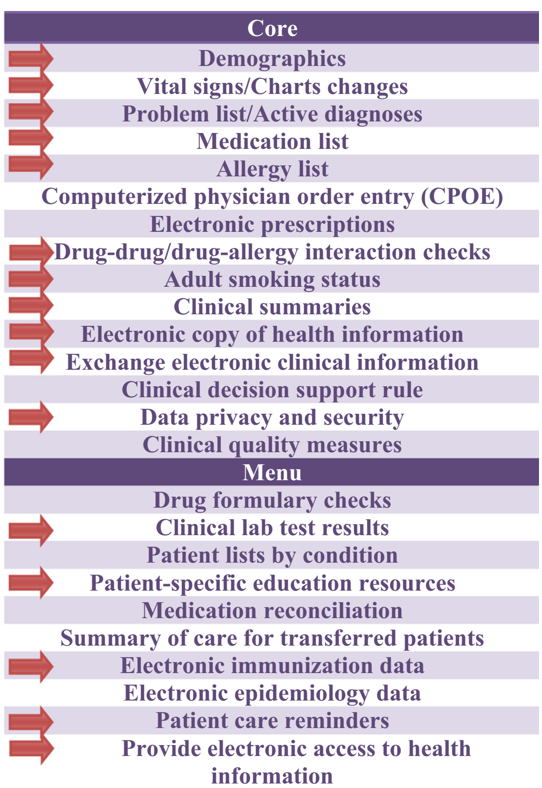

Fig. 4. ONC Meaningful Use criteria for EHRs.

- Recording of the treatment process related data such as treatment procedures (surgeries etc.), medications and hospitalizations.

We define the specification of a patient's problem, its diagnosis and its treatment, *a health triplet*. The PDT basic category includes all functions that are related to the recording of health triplets. The data that are recorded by these functions are official facts generated by healthcare providers.

The second category is called Self Health Monitoring. This category includes functions that help the patient to monitor his own health status. For example, this category may include functions that assist the patients to record their blood pressure, diet, general thoughts and observations of daily life (ODLs). The data items recorded by functions in this category are unofficial and generated by the patient. However, this information may prove very useful in the disease diagnosis and treatment as well as wellness management processes.

The third category is called Communication Management. This category includes functions that help the patient manage his communications with other individuals that are related in his healthcare. More specifically, this category's functions provide services that are not limited to:

- Appointment scheduling.
- Appointment reminders.
- Recording of healthcare professionals' information (name, phone, email, addresses etc.).
- Communication messaging service to healthcare professionals (for prescriptions renewal, drug refill etc.).

In general the functions of this category automate some processes and assist the patient in the communications that must take place in his health care.

The forth category is called Security and Access Control and includes all the functions that are related to the access control and security mechanisms of a PHR system, such as Authentication (verify that the user is who he claims to be), Authorization (verify that the authenticated user has the right to access the resource that he requests), Audit (capturing all access events in the system) and Delegation (user ability to transfer access rights to other users) and Data Security (encrypted data exchange and data storing). In general this category includes security related functions, but the most interesting functions and the most rarely found in PHR systems are the ones that are related to delegation of access rights. For example, the delegation of access rights from a patient, to a portion of his PHR that is applied to a healthcare provider is generally very useful and may prove crucial in some occasions. Consider the case of an emergency situation, which involves a patient's allergic reaction. In this case, the delegation of access to PHR's allergy-related data, to a clinician, is critical. Delegations of access rights are also useful for the automation of process that requires clinician's data (e.g. test results) to be provided to a patient. A delegation of access, allows the clinician to automatically add information regarding test results which can be easily viewed by the patient, avoiding time consuming meetings.

The last category is called Intelligence Factors and includes all functions that illustrate intelligent behavior. More specifically, this category's functions provide services that are not limited to:

- Additional educational resources (e.g. presentation of links to health information).
- Intelligent data presentation (data overview, data filtering, data sorting etc.).
- Intelligent data export (useful formats for system interoperability and presentation).
- Intelligent system alerts.
- System rule based recommendations that enhance decision support (e.g. the system may recognize an abnormal patient behavior through the self-monitoring functions and suggest a doctor visit).
- Interaction with other EHR systems and health applications (e.g. some PHR systems include marketplace of other vendors' applications that can be installed easily to the system or have established integration with other EMR systems).

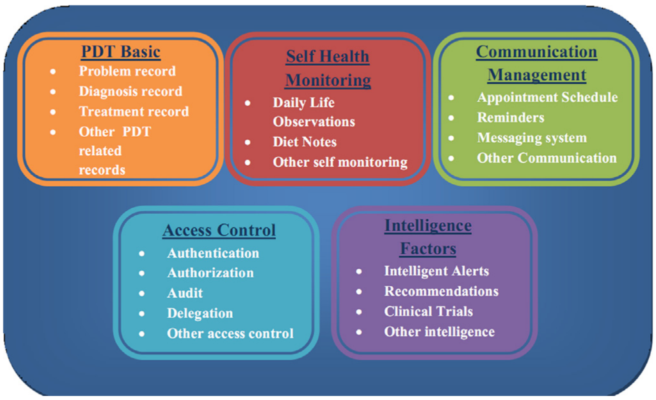

Fig. 5. PHR system functional model.

- Clinical Trials resources and enrolment management.

This functional analysis does not assume completeness on the function list of each category but rather provides a simplified guide to evaluate the functionality of PHR systems, easily. Fig. 5 presents an overview of the simplified functional model that we illustrated earlier.

2.2.4. Architectural and technical requirements

The last optional but desirable requirement is about architectural and technical decisions in the system's development process. The development process should be based on edge computer technologies and sophisticated architectural models. More specifically, the system's architecture should be carefully designed and the implementation should be based on state-of-the-art frameworks, in order to guarantee maintainability, expendability and interoperability. A system that uses outdated frameworks and poor architecture will not survive in this competitive market. In addition, the use of obsolete frameworks delay the development process, in potentially critical system extensions, and may lead users to other solutions, while the poor architectural choices usually influence the systems's extensibility, often resulting in systems which are impossible to functionally extend.

Based on their architectural design, PHR systems are categorized in *standalone*, *tethered* and *interconnected* (which are also called integrated or collaborative) solutions [30,31,3]. *Standalone* PHR systems do not automatically interact with other EHR systems, and patients are responsible for keeping them up to date. These systems can either be web-based that enhance accessibility or desktop applications (that require installation in a desktop PC) or even portable flash-drive applications. However they cannot connect with any other clinician-controlled system and are managed only by patients. *Tethered* PHR systems are provided as part of a larger EHR system which contains a patient portal. These systems are tethered in the sense that they are usually linked to a clinician-controlled health system, and the records can be easily transferred, within the system's infrastructure. *Interconnected* PHR systems have the ability to support integration with other vendor's (EHR, EMR etc.) health systems and applications. Due to their interconnection with other systems, they are able to collect data from multiple repositories and they can serve as an external repository to which other health systems can connect.

Although significant research has been conducted on analyzing the architectural models and technologies of existing PHR systems, the task of "measuring" how technologically advanced a system, from architectural and technical perspective, is a given system, is not trivial. Therefore, it is of primary importance, that an architectural expert reviews the related specifications. This, of course, cannot be achieved in closed commercial products that do not provide detailed implementation information.

2.2.5. The evaluation model

Based on the previous requirement analysis we formulate our evaluation model which is presented in Table 2. The evaluation model includes the *technological*, *functional* and *architectural* categories which are further analyzed in high granularity. The technological category includes the *free*, *web-based* and *open-source* software characteristics, which are described briefly in the model. The functional category includes functionality characteristics and encompasses five functional subcategories, the *PDT Basic* (*Problem-Disease-Treatment*), *Self-Health Monitoring*, *Communication Management*, Access *Control* (*Security*) and *Intelligence Factors* subcategories, while the functional services of these categories are also listed in the model. The architectural category involves three architectural models for PHR systems, the *interconnected*, *tethered* and *standalone* models which are described in an order that lists first the most sophisticated and comprehensive architectural solutions.

The evaluation model of Table 2 includes all the requirements which are later used for analysis and comparison of numerous PHR system implementations. The requirements are derived as a result of the previous requirement analysis (Sections 2.2.1–2.2.4) and are also identified following an implementation specific analysis. In essence, our EU project experiences verify the validity of the requirement analysis which is described in this paper.

The evaluation model attempts to describe the technological, functional and architectural characteristics present in an optimal PHR system. This model can be used to evaluate the extent to which PHR systems can achieve an optimal functional, technological and architectural level, in order to truly enhance the healthcare process. Based on this model, we used a composite method to evaluate the candidate PHR system implementations. The evaluation method is divided into two phases, in an attempt to filter the examined systems and avoid an extensive functional analysis for all them.

In the first phase, we evaluate the systems regarding the first category of the model, i.e. the W-FOSS requirements. Essentially, we examine which of the three W-FOSS requirements were supported by each PHR system. The systems that supported all three W-FOSS requirements were selected for further functional and architectural analysis. This filtering of the systems is based on the fact that we consider the W-FOSS characteristics as basic requirements for a PHR system regardless its functionality level. Therefore, before proceeding into the functionality evaluation, systems are filtered based on their ability to support all three W-FOSS characteristics.

In the second evaluation phase we analyze the functionality and architecture of the selected systems from the first evaluation phase. Essentially, we examine how many of the specified functional services, of each functional category defined in the evaluation model, are supported by each system, in relation to the total number of services defined in the category. Then we converted this ratio to a scale of five, considering that all services have equal weights. This ratio indicates the extent to which each system can achieve the optimal functionality level defined in each functional category of the evaluation model. In addition, we analyze the architecture of the systems in relation to their existing functionality in order to derive useful conclusions about the interrelation of the architectural and functional characteristics.

The evaluation model of this study does not assume completeness on the specified services but rather provides a simplified guide that can be used to evaluate personal health record system

Table 2
The evaluation model.

W-FOSS technological characteristics	**Functional requirements**					**Architectural requirements**
	PDT basic (problem-diagnosis-treatment)	Self-health monitoring	Communication management	Security and access control	Intelligence factors	
Free license software ***Description***: A desirable characteristic for PHR systems is the free software recommendation in order to avoid the restrictions of proprietary software such as cost and distribution limitations.	**Problem (Symptom) recording** *Description*: A service that will provide the ability to record the clinical problems /symptoms of the patient.	**Self-health monitoring services** *Description*: Services that will provide to the patient the ability to record several aspects of his health status.	**Communication management services** *Description*: Services that will provide to the patient the ability to manage conveniently the communications with other individuals involved in his healthcare.	**Authentication** *Description*: Authentication service is responsible of configuring, if the user is who he claims to be, based on a set of identification criteria (typically username -password).	**Intelligent factors** *Description*: Services that illustrate intelligent behavior.	**Architectural models** The architectural models of PHR systems are described in an order that lists first the most sophisticated and comprehensive architectural designs. 1. Interconnected model 2. Tethered model 3. Standalone model
		Self-monitoring services: ● Record blood pressure ● Record diet ● Record general thoughts ● Record daily life observations (ODLs) ● Record body weight ● Record activity ● Record heart rate	**Communication management services:** ● Appointment scheduling ● Appointment reminders ● Recording of healthcare professionals' information ○ phone ○ email ○ addresses ● Communication messaging service to healthcare professionals for facilitating health related procedures ○ prescriptions renewal ○ drug refill		**Intelligent services:** ● Health related educational resources ○ Links to health information ● Intelligent data presentation ○ Data summarization ○ Data sorting ○ Data search ● Intelligent data export ○ Useful formats for system interoperability and presentation (PDF, XML) ● Intelligent system alerts ● Intelligent system rule based recommendations that enhance decision support ○ Recognition of abnormal patient behavior through self-monitoring and suggestion of doctor visit	**Interconnected** This architecture supports integration with other vendor's (EHR, EMR etc.) health systems and applications. Interconnected PHR systems enable collection of information from multiple repositories and can serve as external repository to which other health systems can connect.

Table 2 (*continued*)

W-FOSS technological characteristics	**Functional requirements**					**Architectural requirements**
	PDT basic (problem-diagnosis-treatment)	Self-health monitoring	Communication management	Security and access control	Intelligence factors	
					• Interaction with other EHR systems and health applications ◦ Marketplace of other vendors' applications which can be installed easily to the system ◦ Established integration with other EMR systems • Clinical Trials resources and enrolment management	
Web-based *Description*: A desirable characteristic for PHR systems is the web based recommendation in order to enhance accessibility from multiple devices and eliminate the need of downloading and installing software.	**Diagnosis recording** *Description*: Services that will provide the ability to record all the diagnosis related information and diagnostic procedures that take place during the patient's healthcare. **Diagnosis related services:** • Record Diagnostic tests and results from laboratories • Record Diagnostic Surgeries • Record Allergies • Record Immunizations • Record Demographic elements • Record Family History			**Authorization** *Description*: Authorization service is responsible of configuring if a user, that requests to perform an action on the PHR system, has actually the access right for this action. **Audit** *Description*: Audit service is responsible of capturing all activities involving a member's access to the PHR system.		**Tethered** Tethered PHR systems are provided as integral part of a larger EHR system which is usually controlled by clinicians. This tethered architecture enables easy record transfer within the system's infrastructure between patients and clinicians. **Standalone** Standalone PHR systems do not automatically interact with other EHR systems, and patients are responsible for keeping them up to date
Open-source software *Description*: A desirable characteristic for PHR systems is the open source software recommendation in order to be customizable and extendable according to user needs.	**Treatment recording** *Description*: Services that will provide the ability to record all the treatment related information that take place during the patient's treatment. **Treatment related services:** • Record Treatment surgeries • Record Treatment • Record Medications • Record Hospitalizations • Record Physiotherapies			**Delegation** *Description*: Delegation service provides to the patient the ability to delegate access rights (read, write), to a part of his PHR record, to other individuals involved in his healthcare. **Data security** *Description*: Data security services are responsible for encrypted data exchange and storing.		

implementations easily. The model in its current form is independent of the health domain that is applied and lists generic requirements for PHR systems, but can be extended and adjusted with more domain-specific services in order to evaluate the ability of PHR systems to serve specific health environment needs.

The evaluation process was performed by an IT expert that examined the ability of each system to support each of the model's services. The IT expert used data from real patients in order to examine services that required patient input. The systems analysis was performed in a desktop PC (Intel Core i7-2600 CPU 3.40 GHz, RAM 4 GB). Real patients were not involved in this process because this study rather focuses on the technological, functional and architectural evaluation of PHR systems instead of their usability evaluation. However, our method could also be combined with results from usability evaluation studies that provide feedback from real patients on the services that they use most. This feedback could be used as a basis in the application of different weights to our model's functional services, which will indicate the importance of each service in the patient's healthcare process.

3. Results

In the previous sections, we described the process that we used to identify several candidate PHR systems and the method that we selected in order to evaluate these systems. The evaluation method is based on a set of requirements for PHR systems that formulate our evaluation model. In this section we will present the results of the PHR systems evaluation which is performed in two phases.

3.1. First stage of PHR systems evaluation

In this stage we present the evaluation of the twenty five, selected, personal health record systems, based on the *W-FOSS* requirements. Table 3 illustrates which of the W-FOSS requirements are fulfilled by each personal health record system. The basic conclusion from this evaluation process is that a very small percentage of personal health record systems satisfy the W-FOSS requirements.

Table 3
First stage of PHR system evaluation.

PHR systems evaluation phase 1	Free	Web-based	Open source
Microsoft HealthVault	√	√	X
Web MD Health Manager	√	√	X
NoMoreClipboard	√	√	X
PatientsLikeMe	√	√	X
Patient Ally	√	√	X
Patient Fusion	√	√	X
MyOscar	√	√	√
myMediConnect PHR	√	√	X
eclinicalWorks Patient Portal	X	√	X
MedHelp PHR	√	√	X
MyALERT	X	√	X
CareZone PHR	X	√	X
Indivo-X	√	√	√
Epic MyChart	√	√	X
911 Medical ID	X	X	X
zweena PHR	X	√	X
MedicAlert	X	√	X
Tolven	√	√	√
HealtheTracks	X	√	X
LifeLedger	X	√	X
OpenMRS	√	√	√
KIS PHR	X	√	X
MedicKey PHR	X	X	X
Dossia	√	√	X
Minerva Health Manager	X	√	X

3.2. Second stage of PHR systems evaluation

In this stage we evaluate the functionality and architecture of the selected PHR systems. This evaluation phase is based on our previously described, simplified evaluation model (Table 2).

As stated earlier, in an attempt to avoid extensive functional analysis for all the selected systems, we decided to filter the systems based on their ability to support all three W-FOSS characteristics which we consider as the basic requirements for a PHR system regardless its functional complexity.

For this evaluation phase, we selected the four PHR solutions (MyOscar, Indivo-X, Tolven and OpenMRS), of the first phase, that support all the W-FOSS requirements. We consider only these systems suitable for further analysis and evaluation of their functionality and architecture. Although, only these systems are considered truly suitable to proceed in the second phase of the evaluation process, we decided to select an additional set of six proprietary PHR systems (NoMoreClipboard, eClinicalWorks, Web MD, HealthVault, Patient Fusion and Dossia) which have the highest number of reported users, from the sample systems of stage one. Given the high popularity and potential impact that these systems may have in patients' health management, we decided to include them in the second phase of the evaluation process. As a result our sample space includes ten PHR systems which are evaluated based on their functionality and architecture.

The functional evaluation was based on the functional categories of Table 2. Essentially, we examined how many of the defined services of each functional category are supported by each system with regard to the total number of services in the category. This ratio is converted to a scale of five and indicates the level of accomplishment of each system, to the optimal functionality level defined in each functional category.

Fig. 6 presents the quantitative results of this process. The numbers in the *x*-axis refer to the corresponding system numbering of Table 1. The basic conclusion that is drawn from Fig. 6 and Table 3 is that most PHR systems do not satisfy the functional and technological criteria that we specified.

In Fig. 6, we also present the architectural models of the previously evaluated PHR systems. The basic conclusion that is drawn, from the analysis of their architecture and functionality presented in Fig. 6, is that the interconnected solutions are clearly superior to the tethered and standalone, regarding their functionality. This is a logical conclusion considering that their architecture enhances interconnection with other systems and applications.

However the results in Fig. 6 do not lead to the conclusion that tethered systems are functionally superior to standalone, or vice versa. Sophisticated tethered solutions exist that provide more functionality than standalone solutions, whilst there are poor tethered implementations that do not. Generally, in the tethered architectural model design, the PHR is provided as part of a larger EHR system, thus it is upon vendor's discretion, how much effort will be devoted to the functionality of the PHR system.

4. Discussion

The work presented in this paper provides a composite evaluation model that attempts to describe the requirements that should be met by efficient PHR systems. Our model includes the *technological*, *functional* and *architectural* requirement categories which are analyzed in high granularity. The ultimate objective of the present work, capitalizing on the real-life implementation experiences from several EC funded projects, is to contribute to the

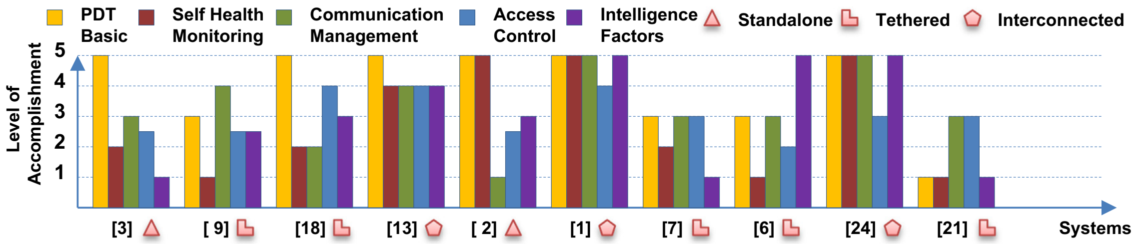

Fig. 6. Second stage of PHR system evaluation.

understanding of the optimal technological functional and architectural characteristics of PHR systems and also use this analysis to assess, the extent to which current PHR systems meet the desirable requirements of our model's categories. This work is complementary to the evaluation studies of PHR systems which are presented in [10–20]. In specific the studies in [10–13] focus on the evaluation of the usability of PHR systems and the provision of generic design recommendations, whereas research in [14–17] identified various problems and open issues for the adoption of PHR systems. Finally, studies in [18–20] focus on defining functional requirements that should be met by effective PHR systems and which can be used for systems analysis and comparison.

The present work also attempts to address the limitations of the previous studies presented in [10–20]. Specifically, the relevant studies [10–17] do not specify distinct evaluation criteria for PHR systems, but rather serve as starting points for requirements elicitation of efficient PHR systems. These studies provide raw material for improving design processes but do not interpret their results into functional requirements or relate them to well-established high level functional standards. In addition, the studies in [18–20] analyze the requirements of effective PHR systems in detail, and utilize them in the evaluation process of specific PHR system implementations. However, the work in [18] is limited with regard to the selected comparison criteria and does not evaluate the PHR systems in aspects such as Communication Management Services and Intelligence Factors (Intelligent Clinical Trials Management, Intelligent Recommendations and Alerts). Equally, the research reported in [19,20] is limited with regard to the number of evaluated systems. The study in [19] compares only two systems from which the one is no longer available while the study in [20] evaluates only one research project in Finland.

The results of this study demonstrate that only a limited number of PHR systems exhibit an almost optimal level of functionality while most of them have functional limitations in various functional categories such as Self-Health Monitoring, Communication Management, Access Control and various Intelligence factors. This conclusion is in line with the findings of [18–20] regarding the functionality limitations of current PHR systems which impose barriers to their adoption and use.

An additional conclusion derived from the results of this work is that only a small number of the evaluated systems are based on the interconnected architectural model while most solutions are based on the tethered architecture. Although the interconnected model seems to be related with functionally superior implementations, (which is a logical conclusion in line with the findings of [31,32,3] since this model enhances EHR systems interconnection) very few of the evaluated systems are designed in compliance to this architectural model.

In general, the results of the present study reveal the need for more careful and comprehensive architectural design and development of PHR systems based on well-established functional and architectural models in order to truly enhance self-health management and clinical care processes. In addition, future research on the field should focus not only in the evaluation of PHR systems functionality and architecture, but also on other critical aspects such as the evaluation of the accessibility of PHR systems by disabled and elderly people, which require more specialized assistance in order to manage their healthcare, and also the evaluation of the quality of information in PHRs which can be created by non-professionals such as patients and wellness providers.

5. Conclusion

In this paper we presented a thorough evaluation study on personal health record systems. This work provides a composite evaluation model that attempts to describe the optimal technological, functional and architectural characteristics of PHR systems. In addition, it presents an overview on the current state of PHR systems, based on the evaluation of numerous available implementations. The study complements other related research efforts which, in our view, exhibit various limitations. The results of the present work can therefore be used as a basis for future evaluation studies which should be conducted periodically as technology evolves and requirements are revised. The evaluation study revealed that regardless the growing number of PHR systems, there is much more to be done in tailoring PHRs for intelligent patient health self-management and sustainability, as it was indicated from the systems' inability to support important functional and technological characteristics and their poor architectural designs which impose barriers to their maintenance, expendability and use.

Conflict of interest

The authors declare no conflicts of interest.

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