Computers in Biology and Medicine 59 (2015) 175–185

Contents lists available at ScienceDirect

Computers in Biology and Medicine

journal homepage: www.elsevier.com/locate/cbm

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

Irini Genitsaridi [a,*], Haridimos Kondylakis [a], Lefteris Koumakis [a], Kostas Marias [a], Manolis Tsiknakis [a,b]

[a] Computational Medicine Laboratory, FORTH-ICS N. Plastira 100, Vassilika Vouton, GR-71110 Heraklion, Crete, Greece
[b] Department of Applied Informatics and Multimedia Technological Educational Institute, Estavromenos, GR-71004 Heraklion, Crete, Greece

ARTICLE INFO

Keywords:
Personal health record
Personal health record system
Personal health record systems requirements
Evaluation study
Functional analysis
Functional model

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

* Corresponding author. Tel.: +30 2810 391391.
E-mail addresses: genitsar@gmail.com, genitsar@ics.forth.gr (I. Genitsaridi).

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http://dx.doi.org/10.1016/j.compbiomed.2013.11.004

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/.