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# Intelligent Personal Health Record Systems

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**Abstract:** *Personal health record (PHR) systems are a constantly evolving 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 an evaluation study on PHR systems that provides an insight on their current status with regard to functional and technical capabilities and we present our extensions to a specific PHR system. Essentially, we provide a requirement analysis that formulates our composite evaluation model which we use to perform a systems review on numerous available solutions. Then, we present our development efforts towards an intelligent PHR system.*

**Keywords:** Personal Health Record

## I. 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) 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"* [1, 2] .

The potential of personal health records to improve healthcare delivery and reduce costs has been recognized in many countries worldwide [3, 4]. In recent years, numerous PHR systems and their associated tools have been developed [5]. This global interest and phenomenal growth of personal health records systems, motivates an on-going research towards the evaluation of their functionality, usability and usefulness. In this paper, we provide an evaluation study of numerous PHR systems which emphasizes on optimal PHR functionality and presents our development efforts towards an intelligent PHR system.

The contribution of this paper is twofold. First, we provide a simplified yet elaborate evaluation model for PHR systems which we use to perform a PHR systems review. The results of this process provide an insight on the current status of personal health record systems, in terms of functional capabilities and other important technological characteristics. Second, we describe our development efforts that aim in the implementation of a useful, effective and intelligent PHR framework that will satisfy the variety of health environments needs and will foster an optimal user experience. Overall, the results of this paper can serve as a basis for future evaluation and implementation studies which should be conducted periodically in the constantly evolving field of PHR systems.

The rest of this paper is organized as follows: Section 2 presents the limitations of the related work that justify our study. Section 3 provides a thorough requirement analysis that formulates our evaluation model while section 4 discusses the application of this model in the comparison of numerous PHR system implementations. Section 5 describes our implementation efforts, in line with our requirements analysis, towards an intelligent PHR system. Finally, section 6 concludes the paper and discusses future work.

## II. RELATED WORK

The implementation of an ideal PHR system requires an ongoing development effort that will, periodically, be provided with feedback from evaluation studies in order to reach optimal functionality, architecture and technical specifications. In recent years, numerous PHR systems have been proposed and several evaluation studies have been reported [6-16]. The studies presented in [6-9] focus on the evaluation of the usability of PHR systems and identified usability related issues in specific systems. Research reported in [10-13] analyzed various barriers to the adoption of PHR systems and

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challenges that should be addressed while studies in [14-16] analyze functionality limitations of PHR systems and attempt to define PHR system requirements. Overall, these studies provide important recommendations for improving design processes and generally reveal that most PHR systems suffer from serious limitations. This is a motivation for future PHR systems development or current PHR systems extension that will take into consideration these findings to provide improved, user-friendly and efficient solutions.

In addition, more evaluation studies should also be conducted, to complement current research [6-16] which, in our view, exhibit various limitations. The [6-13] studies do not specify distinct evaluation criteria for PHR systems, but rather serve as starting points for requirements elicitation. On the other hand, the studies in [14-16] 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 [14] is limited with regard to the selected comparison criteria. The study does not analyze the completeness of each system towards the specified requirement categories, but rather identifies the presence or absence of a limited set of features. Equally, the research reported in [15, 16] is limited with regard to the number of evaluated systems. The study in [15] compares only two systems from which the one is no longer available while the study in [16] evaluates only one research project in Finland. While there is a significant body of published research results, as mentioned above, it is also evident that *"...more research is also needed that addresses the current lack of understanding of optimal functionality and usability of these systems, and how they can play a beneficial role in supporting self-managed healthcare*." [17].

## III. REQUIREMENT ANALYSIS

In this section we analyze the basic requirements for a powerful, customizable, extendable and intelligent PHR system. These requirements formulate an evaluation model which we later use for PHR systems evaluation.

### The FOSS Requirement

The use of PHR systems is facilitated by the *F*ree and *O*pen *S*ource *S*oftware (FOSS). The free (license) concept intends to free users from any restrictions of proprietary software such as cost and distribution limitations while the open source concept aims to provide them with the ability to modify the software according to their needs. FOSS solutions often provide better quality and technical support because of the worldwide involved community. When FOSS is applied to the field of PHR systems, the resulting solutions guarantee full access to the source code, reduced enterprise related risks, and free license to copy, distribute and change the software according to healthcare environment needs. For all these reasons, we consider the free and open source nature of a PHR system as a basic requirement for its adoption.

### 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 PHR data, 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, giving so the ability to access the PHR not only through a computer but also through a smart phone or a tablet pc. The new emerging area of m- health [18] supports further this requirement.

### Functionality Requirements

A PHR system needs to be in compliance with high quality functional standards, in order to be acknowledged as a fully functional, secure product. In this direction, we have distinguished the Personal Health Record System Functional Model (PHR-S FM) [19]. Based on the study of the PHR-S FM and a thorough functionality analysis of numerous PHR implementations, we formulated our simplified yet comprehensive functionality evaluation model which is composed of five coarse-grained function categories and services descriptions in higher granularity.

The first category is called Problem, Diagnosis and Treatment (PDT) Basic and encompasses related functions. 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 (e.g. patient problem recording, diagnostic tests and treatment surgeries). 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 a function that assists the patient to record his blood pressure, diet, general thoughts and observations of daily life (ODLs). The data that are recorded by functions in this category are unofficial and generated by the patient. However, this information may prove very useful in the diagnosis and treatment processes.

The third category is called Communication Management. The category includes functions that help the patient manage efficiently his communication with other individuals that are related in his healthcare

This category encompasses services that are not limited to appointment scheduling, reminders, messaging service to healthcare professionals (for drug refill prescriptions renewal) In general the functions of this category automate some processes in the patient's healthcare and assist the patient in the communications that must take place during his treatment and monitoring

The forth category is called Access Control and includes all the functions that are related to the access control of a PHR system, such as Authentication, Authorization, Audit (AAA) and Delegation of access rights. It's worth noting that the delegation of rights to a patient's clinician can be proved crucial in an allergic reaction or other health related critical incidents

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, educational r , intelligent data presentation and export, efficient interaction with other health systems, smart recommendations to patient and clinicians, clinical trials recommendations and enrolment

management This functional analysis does not assume completeness on the function list of each category but rather provides a simplified yet comprehensive guide to evaluate the functionality of PHR systems, easily.

**Architectural and Technical Requirements**

The last optional but desirable requirement is about architectural and technical decisions in the system's development process. 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. In the field of personal health record systems, there are three commonly used architectural models the standalone, tethered and interconnected models [20 21 1]. Standalone PHR systems do not automatically interact with other electronic health record (EHR) systems, and patients are responsible for keeping them up to date. Tethered PHR systems are provided as part of a larger EHR system and are thus internally linked to a clinician controlled health system In tethered systems records can be transferred easily, within the system's infrastructure. Interconnected PHR systems ar more sophisticated systems that support collaboration with other vendor's (EHR, EMR etc.) health systems. Due to their interconnection with other systems, they are able to collect data from multiple repositories and they serve as an external repository to which other health systems can connect.

**Requirements Summary**

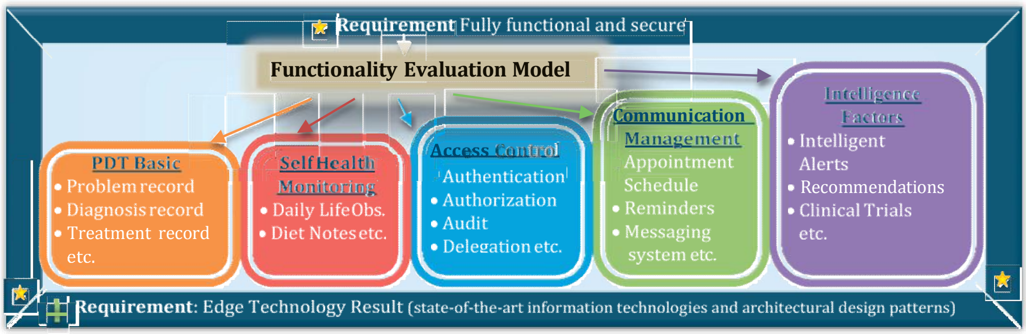


Fig. 1 PHR systems evaluation model

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Figure 1 presents an overview of our composite evaluation model. The light blue area depicts the comprehensive functionality model that we described in detail earlier in section 3.3 The ar a marked with a yellow point star symbol indicate basic requirements while the ones marked with green plus symbol indicate desirable but optional requirements for an efficient PHR system

## IV. SYSTEMS REVIEW

In this section use the requirements that we previously analyzed as criteria to evaluate m r PHR system solutions, which identified following a methodological approach described in [22] Table . First Stage of PHR system review

| | |
|---|---|
| Review | 2 4 6 7 9 10 2 13 4 15 16 17 18 19 20 2 22 23 24 25 |
| Free | ✔ ✔ ✔ ✔ ✔ ✔ ✔ ✔ ✘ ✔ ✘ ✘ ✔ ✔ ✘ ✘ ✘ ✔ ✘ ✘ ✔ ✘ ✘ ✔ ✘ |
| Web based | ✔ ✔ ✔ ✔ ✔ ✔ ✔ ✔ ✔ ✔ ✔ ✔ ✔ ✔ ✘ ✔ ✔ ✔ ✔ ✔ ✔ |
| ✔ ✘ ✔ ✔ Open Source | ✘ ✘ ✘ ✘ ✘ ✘ ✔ ✘ ✘ ✘ ✘ ✘ ✔ ✘ ✘ ✘ |
| ✘ ✔ ✘ ✘ ✔ ✘ ✘ ✘ ✘ | |

The evaluation process is conducted in two stages In the first stage we present the evaluation of twenty five PHR systems, based on the Web based, Free and Open Source requirements which we define a *W FOSS* Table illustrates which of the W FOSS requirements are fulfilled by each PHR system. The basic conclusion drawn from this evaluation process is that a very small percentage of PHR systems satisfy the W FOSS requirements. ubsequently, in the second evaluation stage we evaluate the functionality of ten representative PHR systems from stage n and nalyze their architectural models in relation to their existing functionality. Figure 2 presents the architectural models of the PHR systems and also illustrates the level of accomplishment of each PHR system, to each function category of previously described, functionality model in a scale of five We have to mention that the aforementioned evaluation was performed by an IT expert. However due to space restrictions we do not describe the process in detail From this process we conclude that most PHR systems do not satisfy the functional requirements that we have specified and 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, we cannot conclude that tethered systems are functionally superior to standalone, or vice versa. There exist, sophisticated tethered solutions that provide more functionality than standalone solutions, and 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.

The systems numbering corresponds to the following PHR system solutions.

1: Microsoft HealthVault (healthvault.com),

2: Web MD Health Manager (webmd.com/health manager),

3: NoMoreClipboard (nomoreclipboard.com),

4: PatientsLikeMe (patientslikeme.com),

5: Patient Ally (patientally.com),

6: Patient Fusion (practicefusion.com),

7: MyOscar (myoscar.org),

8: myMediConnect (passportmd.com),

9: eclinicalWorks (eclinicalworks.com),

10: MedHelp
(medhelp.org), 11: MyALERT (alert online.com),

12: CareZone (carezone.com),

13: Indivo X (indivohealth.org),

14: Epic MyChart (epic.com),

15: 911 Medical ID (911medicalid.com),
16: zweena (zweenahealth.com),
17: MedicAlert (medicalert.org),
18: Tolven (tolven.org),
19: HealtheTrack (healthetracks.com),
20: LifeLedger (elderissues.com),
21: OpenMRS (openmrs.org),
22: KIS (kismedicalrecords.com),
23: MedicKey (medickey.com),
24: Dossia (dossia.org),
25: Minerva Health Manager (myminerva.com)

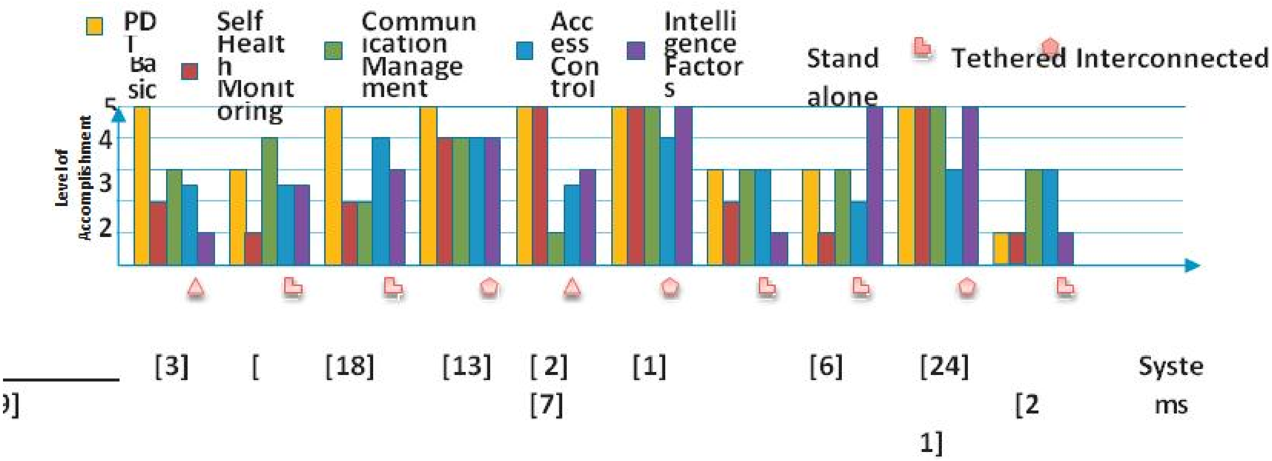


Fig. 2. Second Stage of PHR * systems review

## V. PERSONAL HEALTH RECORD FRAMEWORK

In this section we describe our development efforts towards an intelligent PHR system. Essentially, we selected an efficient PHR system based on the results of the previously described evaluation process and extended it into further intelligent behavior. The evaluation results which were presented in section 4 revealed that the most appropriate PHR system, according to our specified requirements, is the Indivo-X PHR system. Other PHR systems with high level of functionality are the Microsoft HealthVault and Dossia systems. However these systems did not fulfill the W-FOSS requirements (Table 1) in the first evaluation stage. On the other hand, the systems Tolven, MyOscar, and OpenMRS which were successful on the W-FOSS requirements presented limited functionality compared to Indivo-X system. Having selected our PHR system we decided to customize and extend further its intelligence factors. In the following subsections we describe our software additions to Indivo-X and argue about our extensions. However due to space restrictions we do not explain them in detail.

### Intelligent Data Exchange

Since PHR consolidate patient health information, it is of great benefit to be able to share this integrated, comprehensive source of health information with health care providers and/or other family members [23]. This could potentially bridge gaps in understanding, promoting more effective patient- provider dialogue, and improving care coordination for patients seeing multiple providers.

To this direction, we have extended Indivo-X in order to be able to communicate with other health systems. Indivo-X has already implemented mechanisms for exporting data as JSON, XML and RDFS. However, although this is useful, most of the systems in the health domain understand HL7 messages. So, we have implemented an adapter that can transmit HL7 messages. We have to note that the content of this HL7 messages is also compatible with well-established terminologies such as SNOMED, RxNorm and LOINC. For data sharing, the patient can either accept to share data with a specific family member of health care provider or he can directly export his data to an HL7 message consumer.

On the other hand besides exporting, importing is also a useful functionality since usually PHR systems require the error-prone and time-consuming process of manual data entry. So, in our case we extended the Indivo-X system to accept HL7 messages that directly insert patient data. Another import functionality that we provided is to link Indivo-X to other systems that can answer SPARQL queries. So, forms, lists etc. can be directly retrieved from SPARQL endpoints and stored within Indivo-X database.

This way, information is made more useful to the patients and can play a larger role in their health care.

**Profiling Services**

A profiling server collects information from different sources and combines them to construct patient profiles. Incorporating a profiling server give us the ability to (i) optimize information delivery from doctors to patients, (ii) optimize information delivery to patients according to each specific profile and identify relevant clinical information, such as trials for enrollment, automatically.

Central sources for our profiling services approach are the PHR (with its extensions) and the patient's psycho-cognitive information. Towards this direction we have implement a patient profiling questionnaire which is incorporated into the Indivo-X PHR system as an extension.

**Profiling Questionnaire**

A patient profiling questionnaire must be short and easy to use, with the ability to measure four broad areas: (i) Perceived health state: The way a patient perceives his/her own health state is determining his/her quality of life to a large degree, (ii) psychological aspects: Mainly psychological distress, which includes anxiety as well as depressive symptoms, (iii) psychosocial aspects such as social abilities and financial problems and cognitive aspects: cognitive functioning is expected to influence a patient's ability to function, thereby negatively impacting his/her quality of life. Subtle changes in cognitive abilities are sometimes difficult to detect.

A detailed description about the ALGA questionnaire can be found at [24]. Data generated by the questionnaire will be used to monitor the patient's quality of life, thereby facilitating the patients' involvement in the clinical decision process. Including patient profiling data into the treatment process has a positive influence to the patient's emotional functioning and the communication between the physician and the patient is facilitated and improved.

**Patient Profiling Server**

The patient profiling server will also provide the necessary services for combining the different sources. Information collected from the PHR, EHR and the questionnaire will be exploited in conjunction with the provided knowledge discovery tools, in order to form a platform for the patient empowerment.

The aim of the server is to provide the necessary methods and algorithms to collect, merge and analyze the patient's data. The server will be able to develop a patient profile and to operate as an integrated analysis environment for patient data analysis and knowledge discovery tools.

A variety of knowledge discovery tools exists in the public-domain like Weka (http://www.cs.waikato.ac.nz/ml/weka/), R-package/Bioconductor (http://www.bioconductor.org/) and BioMoby (http://biomoby.org/). We focus on a specific domain of knowledge discovery algorithms in order to discover patterns using Data Mining techniques.

**Recommendation Services**

Currently, registering patients into clinical trials and finding eligible trials for patients require manual search and clinicians may be overwhelmed by the number of clinical trials and the exclusion and eligibility criteria. Having access to multidimensional, complementary data, automatic recommendation services can be implemented for patients or doctors.

As an example, consider the registration of patients into clinical trials. Though automatic matching, we expect to reduce the search space with respect to the number of patients, CTs and exclusion/inclusion criteria that need to be manually reviewed. Since the options are limitless, we will design the recommendation server modular and extensible in order to be able to add different functionalities employing different algorithms and mechanisms.

## VI. CONCLUSIONS AND FUTURE WORK

In this work, we have provided an extensive analysis on the requirements that must be satisfied by an effective and intelligent PHR system which led to the formulation of a simplified yet comprehensive evaluation model. Subsequently, we used this model to evaluate numerous available PHR systems, providing thus an overview on their current state. Finally, we described our current development efforts towards an intelligent PHR system that involved extensions in the Indivo-X PHR system with regard to intelligence factors such as intelligent data exchange, profiling and recommendation services.

Interesting future directions for our work and the generic PHR systems research field are timidly addressed in [25, 26, 27], including the accessibility of PHR systems from elderly and disabled people and the evaluation of data quality in a PHR system that may be generated by non-professionals such as

patients and wellness providers. Another important topic for future research remains the clinical effectiveness and cost effectiveness of PHR systems utilization that has not been adequately confirmed.

Overall, the results of the present work can be used as a basis for future evaluation and implementation oriented studies on PHR systems, which should be conducted periodically as technology evolves and requirements are revised

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