Integrated Care Solutions for the Citizen: Personal Health Record Functional Models to Support Interoperability

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Abstract

The ever-growing demand for acquiring, managing and exploiting patient health related information has led to the development of many e-Health systems and applications. However, despite the number of systems already developed and the apparent need for such systems, end users can only collect online and exploit, only a limited set of information for health purposes in the context of personalized, preventive and participatory medicine. To this direction, this paper initially presents the personal health record (PHR) concept, related work and best practices for the development of PHR systems in a standardized manner. It also outlines the proposal for meaningful use criteria in the United States (US) and the health level seven (HL7) personal health record system functional model (PHR-S FM). Focus is put on trying to link core functionality modules of the Integrated Care Solutions ™ PHR system, designed to support the citizen, paying emphasis on wellbeing, home care and the management of chronic diseases with PHR-S FM personal health functions, in a preliminary effort towards the exploration of functional models to support interoperability. Based on accumulated experiences from many European Union (EU) research projects, the paper concludes by providing directions towards achieving wider PHR adoption and meaningful use.

Keywords

Personal Health Record; Integrated Care; Meaningful Use; PHR-S FM

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1 Introduction

The Personal Heath Record is a tool designed for the citizen with the goal to promote continuity of care in a reliable, accessible and secure fashion. The main expected benefit is to empower both patients and clinicians towards a more synergistic, patient-centric healthcare, promoting shared care and personalized medicine throughout a citizen's lifespan. The idea of a PHR has been developed in parallel with the development of the Electronic Health Record (EHR). The PHR was first mentioned in an early report from the US Institute of Medicine called 'The Computer-Based Patient Record: An Essential Technology for Health Care' [1]. The report described the envisaged requirements of such an endeavour. In Europe the PHR concept has been introduced through European Directive 95/ 46/ EC [2], which first allowed/ proposed the direct interaction of the person with his/ her health record including input of data from home, work and leisure places [3]. It is a fact that the advancements in healthcare practice, the limitations of the traditional healthcare processes and the need for flexible access to health information, create an ever-growing demand for electronic health systems everywhere. To this direction, PHR systems provide citizens with the ability to become more active in their own care combining data, knowledge and software tools. The PHR concept is citizen centric, in the sense that its management is the primary responsibility of the citizen. Through a PHR application, the citizen/ patient is able to provide daily life-status information, maintain his/ her own record of medical exams and define the access rights to own personal data, leveraging that access to improve own health and manage own diseases.

Over the last twenty years a large amount of PHR-like systems have been developed such as: 911 Medical ID (http://www.911medicalid.com/), CareZone PHR (https://carezone.com/), Dossia (http://www.dossia.org/), eclinicalWorks Patient Portal (http://www.eclinicalworks.com/products-patient-portal.htm), Epic MyChart (http://www.epic.com/software-phr.php), HealtheTracks (http://www.healthetracks.com/), Indivo-X (http://indivohealth.org/), KIS PHR (http://kismedicalrecords.com/), LifeLedger (http://www.elderissues.com/), MedHelp PHR (http://www.medhelp.org/), MedicAlert (http://www.medicalert.org/), MedicKey PHR (http://medickey.com/), Microsoft HealthVault (http://www.microsoft.com/en-gb/healthvault/default.aspx), Minerva Health Manager (http://www.myminerva.com/), MyALERT (http://www.alert-online.com/myalert), myMediConnect PHR (http://www.passportmd.com/), MyOscar (http://myoscar.org/), NoMoreClipboard (http://www.nomoreclipboard.com/), OpenMRS (http://openmrs.org/), Patient Ally (https://www.patientally.com/Main), Patient Fusion (http://www.practicefusion.com/pages/phr.html), PatientsLikeMe (http://www.patientslikeme.com/), Tolven (http://www.tolven.org/), Web MD Health Manager (http://www.webmd.com/health-manager), zweena PHR (http://www.zweenahealth.com/), and others.

However, despite the wide variety of potential benefits [4] the uptake of PHRs has been proven to be really slow [5]. Recent reviews [6, 7] identify as a problem the fact that only a small subset of the PHR applications are free, web-based and open-source. Nevertheless, many different business models exist, fee-based or commercial, complicating even more the selection of an appropriate PHR. In addition, the main problems, still pending to be resolved, are the following:

Interoperability: PHR systems are rarely integrated and interoperable with other electronic service providers [8, 9]. In most of the cases, end-users need to enter the whole amount of input information by themselves.

Usability/ Adaptability: The majority of PHR systems follow the approach "one system fits all". However, different persons with different primary diseases have different needs and the PHRs so far fail to be adapted to specific needs [10].

Trust: The limitations of the methods for sharing information among patients, and their relatives, doctors and researchers. There is a sense of lack of trust as well as inefficient access control and security mechanisms [6, 11, 12].

Added Value: PHR systems are not linked with specific services. The added-value for citizens to maintain a personal health file through manual input of data has not been adequately demonstrated [6, 7, 12].

To face these challenges guidelines and standards are starting to emerge to support quality PHR systems like the US Meaningful Use Criteria [13], and the HL7 PHR-S FM [14, 15]. However, the adoption of those is still limited.

This paper focuses on the presentation of a beyond-the-state-of-the-art PHR system, which is interoperable, personalized, and adaptable for various diseases. It has been designed for easy integration with existing clinical information systems. Its development has been based on the outcomes of various EU research projects and exhibits a high technology readiness level. The PHR provides effective and efficient access control mechanisms and many added-value services. The goal of the presented system is to provide an innovative ecosystem for enhancing the self-management capacity of patients through the involvement of all stakeholders participating in the therapeutic process.

The structure of the rest of this paper is as follows: Section 2 describes the methods used. Then preliminary results are reported in Section 3. Finally, Section 4 concludes this paper and presents directions for future work.

2 Methods

In order to conduct this work, literature review was performed on established work, and additional information was retrieved from published material and web sites in order to identify current trends and good practices. In the following subsections, a short presentation is made of the US Meaningful Use Criteria, the HL7 PHR-S FM R1, and the related European research and development projects that have guided the design and development of the PHR system presented. The different models and projects have been selected to emphasize the functionalities that are required to support efficient PHR adoption.

2.1 Meaningful Use

The US Meaningful Use (MU) Criteria [13] were initially introduced as an EHR incentive. Later on, they were adopted also as a guideline for PHR systems, since they include specific requirements for patient engagement, as seen in Stage 2 of the MU program [16]. Since 2014, in order to meet the requirements of the Centers for Medicare & Medicaid Services (CMS) EHR Incentive Program, healthcare providers must provide a patient portal. The Healthcare Information and Management Systems Society (HIMSS) identified the "required" and the "helpful" core and menu objectives that the patient portals should support or consider to support in order to allow patients to interact with their healthcare provider [17], from the complete list of the MU Stage 2 program (17 core measures and 6 menu measures). The minimum core objectives for a PHR, connected to an EHR, include a mechanism to provide patients the ability to view online, download and transmit their health information, and a secure electronic messaging system to communicate.

The MU program is using certified EHR technology to reduce health disparities and improve quality, safety, and efficiency of healthcare [18]. Having guaranteed data capture and sharing, MU stage 2 aimed towards improved outcomes through the advancement of clinical processes. The patient is expected to be able to access their health information on demand through a patient portal or PHR. As reported in [19], the PHR products available as of 2014 are likely to meet and exceed meaningful use stage 3 targets before 2020 without any incentive.

2.2 HL7 Personal Health Record System Functional Model, Release 1 PHR-S FM

The HL7 PHR-S FM, which is a Draft International Standard: ANSI [20]/HL7 PHRSFM, R1-2014; ISO/FDIS 16527:2013(E) [21], defines a standardized model of the functions that may be present in a PHR System (PHR-S). According to HL7, the PHR is the underlying record (e.g., data, information, pictures, sounds, graphs, videos, etc.) that the software functionality a PHR-S maintains. Depending on the functionalities applicable for a particular business case, certain PHR functions and criteria in the PHR-S FM will apply to any single PHR-S implementation. This, more concrete, expression of usable subsets of functions from the PHR-S FM is called *functional profile*. This profile is the standard description and common understanding of the requested or available functions in a given environment. The intention is for all functions describing the behaviour of a system, in a consumer-oriented language, to be recognizable to all key stakeholders of a PHR-S. PHR-S FM consists of three main sections: Personal Health, Supportive, and Information Infrastructure, as outlined in Table 1.

Table 1: The PHR-S functional outline.

PHR-S Function List Sections	ID#	Superset of functions
Personal Health	PH.1.0	Account Holder Profile
	PH.2.0	Manage Historical Clinical Data And Current State Data
	PH.3.0	Wellness, Preventive Medicine, and Self Care
	PH.4.0	Manage Health Education
	PH.5.0	Account Holder Decision Support
	PH.6.0	Manage Encounters with Providers
Supportive	S.1.0	Provider Management
	S.2.0	Financial Management
	S.3.0	Administrative Management
	S.4.0	Other Resource Management
Information Infrastructure	IN.1.0	Health Record Information Management
	IN.2.0	Standards Based Interoperability
	IN.3.0	Security
	IN.4.0	Auditable Records

The Personal Health (PH.1.0-PH.6.0) section functions are the subset of PHR-S functions that manage information and features related to self-care and provider-based care over time. The Supportive (S.1.0-S.4.0) section functions are the subset of PHR-S functions that assist the PHR account holder with administrative and financial requirements. The Information Infrastructure (IN.1.0-IN.4.0) section consists of PHR-S functions that ensure that the PHR-S provides information privacy and security, interoperates with other information systems (including PHR and EHR systems), and helps make PHR-S features accessible and easy to use.

According to HL7 PHR-S FM, in order to ensure the necessary functions in selecting or developing PHR systems, it is important to create accurate, clear and impartial functional profiles by selecting functions from the HL7 EHR-S FM. A functional profile is a selected set of functions that are applicable for a particular purpose, group of users, degree of interoperability, etc. The profile consists of the choice of certain functions that can be mandatory (SHALL), prohibited (SHALL NOT), optional recommended (SHOULD), optional, or permissible (MAY). The goal of creating a functional profile is to support a business case for PHR-S use by selecting an applicable subset of functions from the PHR-S FM. A formal process exists for registering and balloting functional profiles. Testing and certification procedures are then required to ensure that the subsystems and the general PHR-S conform to the selected functional profile and meet the characteristics for the proper operation of the system.

A PHR-S does not conform directly to the PHR-S FM; rather, a PHR-S conforms to a functional profile (i.e., a subset – more specifically, a tailored subset) of the PHR-S FM. Conformance to the PHR-S FM is defined for functional profiles.

2.3 European Projects

The implementation of projects co-funded by the EU, during the past few years, has provided significant experience gains on PHR development, for specific cases. Projects in which the authors of this paper have been actively involved are briefly described below.

REACTION: The REACTION project (http://www.reaction-project.eu/news.php, 2010-2014), aimed to research and develop an intelligent service platform for professional, remote monitoring and therapy management of diabetes patients in different health systems across Europe. As such, the platform is not a general-purpose PHR system but optimized especially for the empowerment of diabetic patients. The constructed platform can execute various clinical applications for monitoring of vital signs, context awareness, feedback to the point of care, integrative risk assessment, event and alarm handling as well as integration with clinical and organisational workflows and external Health Information System [22].

P-Medicine: The p-medicine EU project (http://www.p-medicine.eu, 2011-2015) created an infrastructure that facilitates 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. In the context of the project, a range of services were designed and developed on top of a PHR system. The p-medicine PHR is based on a general purpose PHR (Indivo-X) with extensions towards the directions of cancer patient profiling and clinical decision support for personalized oncology [23]. Furthermore, the project implemented a secure mechanism for informed secondary use of patient's biomaterial and personal data via the PHR [24]. The p-medicine tools and technologies have been validated within the concrete setting of advanced clinical research with pilot cancer trials based on clear research objectives, in the domains of Wilms tumour, breast cancer and leukaemia.

EURECA: The goal of the EURECA project (http://eurecaproject.eu/, 2012-2015) was to enable seamless, secure, scalable and consistent linkage of healthcare information residing in electronic health record (both EHR and PHR) systems with information in clinical research information systems, such as clinical trials. Achieving semantic interoperability among PHR and clinical trial systems was at the core of the EURECA project, as it was the basis for enabling many of the software services and tools developed in the project. Data management services were implemented for a variety of EHR and clinical trial systems (e.g. Obtima, OpenClinica) in order to achieve semantic interoperability with the Indivo-X PHR using terminology standards and HL7 mechanisms for exporting and importing data [6, 11].

MyHealthAvatar: The MyHealthAvatar (http://www.myhealthavatar.eu/, 2013-2016) EU project [25] (FP7) was an attempt for the digital representation of patient health status. The goal was to create a "digital avatar", i.e. a graphical representation/ manifestation of the user, acting as a mediator between the end-users and health related data collections, focusing on the interoperability and the data integration aspect. It was designed as a lifetime companion for individual citizens to facilitate the collection, the access and the sustainability of health status information over the long-term. Among others, key questions that are answered in this context is how to develop optimal frameworks for large-scale data-sharing, how to exploit and curate data from various Electronic and Patient Health Records, assembling them into ontological descriptions relevant to the practice of systems medicine and how to manage the problems of large scale medical data.

iManageCancer: The iManageCancer (H2020) EU project (http://imanagecancer.eu/, 2015-2018), has the objective to provide a cancer specific self-management platform designed according to the needs of patient groups. At the same time, it focuses on the wellbeing of the cancer patient with special emphasis on avoiding, early detecting and managing adverse events of cancer therapy but also, importantly, on the psycho-emotional evaluation and self-motivated goals [26]. In this context, developed cancer specific apps allow patients, through an easy-to-use interface for mobile devices, to keep track of their health and disease status and to keep a health diary on personal clinical observations such as side effects of therapies, which the patient can share with his healthcare providers. Health and disease status includes therapies and results of clinical interventions or tests.

3 Results

Integrated Care Solutions ™ (ICS) is a software suite developed by FORTH and includes several tools and applications for electronic health management. The majority of the already implemented software components of the platform are in operational use in several units of the national health system in Greece [27]. The ICS-C applications, as part of the ICS suite, aims towards directly supporting the Citizen. The Personal Health Record for the Citizen (PHR-C) end-user application belongs to this group of applications. Figure 1 depicts the architectural approach and key modules involved.

PHR data types have evolved since the first PHRs [28]. The components that are common to the EHR and are stored also in the PHR include medications, scheduled appointments, vital signs, medical history (problems list), laboratory information, immunizations, scanned documents, and progress notes about changes in the patient's health. Ideally, the PHR should include as much relevant data as possible over the individual's lifetime, from multiple sources, including health care facilities as well as the individual [29]. The specific data source of each item should be labelled and visible to the user. The more comprehensive the data contained in a PHR are, the more useful the data will be to patients and care providers, although there are no conventions for what data should be contained in a PHR.

PHR-C functionalities and modules can be directly linked to the PHR-S FM. In an effort to depict the relation of core functionality modules with EHR-S FM, towards establishing an initial approach for defining an initial profile to test compatibility against, we have come up with the links depicted in Table 2.

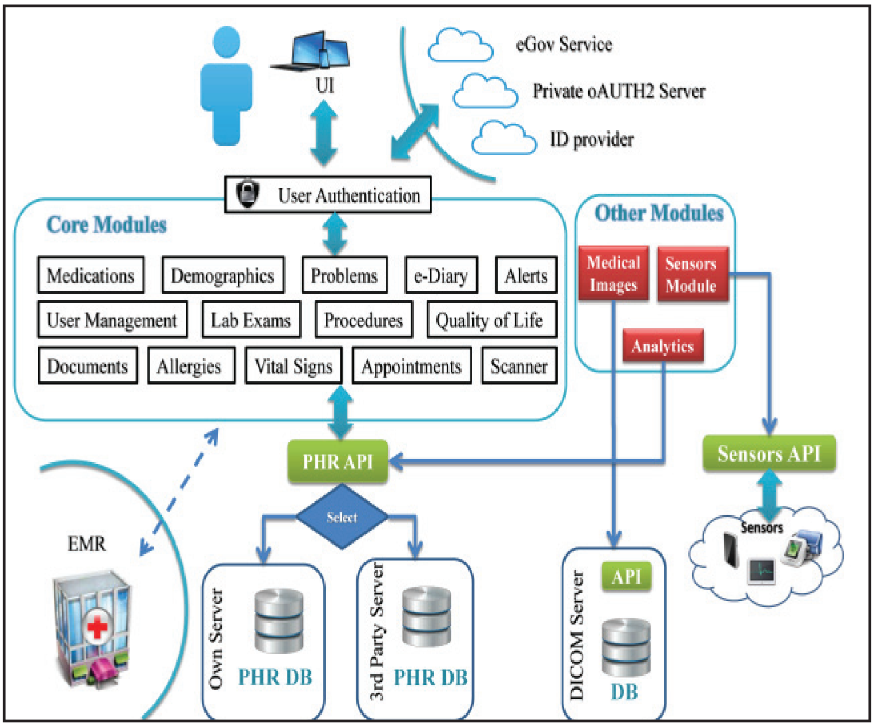

Figure 1: Integrated Care Solutions PHR high-level architecture approach.

Table 2: ICS PHR-C core functionality modules link to PHR-S FM R1 personal health functions.

Name	Potential Sources	Description	PHR-S FM ID#	PHR-S FM Statement
Alerts	PHR, external sources	This app allows the implementation of care management alerting rules to appear in end-user(s) account.	PH.3.5.5	Notify the PHR Account Holder of an event or situation that may need immediate action.
Allergies	PHR, EHR	For recording allergies and related information (allergy name, severity, allergen, adverse reactions, etc.).	PH.2.5.4	Manage the PHR Account Holder's list of known allergens and adverse reactions with all pertinent information.
Appointments	PHR, external providers	To allow an end-user to schedule his appointments. Appropriate reminders are then issued to remind him a specific appointment.	PH.3.5.1	Provide a health calendar to record and display health care events.
Demographics	PHR, eGov Service	For recording demographic information (address, gender, date of birth, etc.)	PH.1.2	Enable the PHR Account Holder to manage information about demographics.
Documents	PHR	For storing personal documents as attachments (discharge letters, prescriptions, PDFs, ECGs, DICOM images etc)	PH.3.1.1	Provide the ability for the PHR Account Holder to enter personally sourced data and to make it available electronically to authorized health care provider(s) or other authorized users or applications.
e-Diary	PHR, external providers	This app allows the diary visualization of all information available in a user profile.	PH.3.5.4	Present the PHR Account Holder with reminders either sent by external sources (such as from provider(s)), or internally generated from information in the PHR-S (such as guideline-based reminders, prescription refills, appointment reminders, or other calendar entries).
Lab Exams	Patient, EHR, commercial laboratories	For recording laboratory results and related information (lab test name, date, value, abnormal values, etc.)	PH.2.5.3	Manage results of diagnostic tests including inpatient, ambulatory and home monitoring tests.

Medications	PHR, EHR, claims history	For recording medication prescribed medicines taken and related information (drug name, quantity, unit, date etc.).	PH.2.5.2	Manage the PHR Account Holder's medication list.
Problems	PHR, EHR	For recording problems and related information (start date, category, details, etc.)	PH.2.5.1t	Manage the PHR Account Holder's health problem list and provide the ability to manage the problem list over time in accordance with organizational policy and/or jurisdictional law.
Procedures	PHR, EHR, or claims	For recording medical procedures and related information (name of the procedure, date performed, institution, cost etc.)	PH.2.5.7	The list of past procedures is a useful summary of what has been done in the past and anatomic changes have occurred that might influence current assessments and treatments. It is important to capture any surgical implants and associated lot/ serial numbers for tracking/ reporting purposes.
Quality of Life	PHR	For recording responses to validated questionnaires to assess the quality of life of individuals.	PH.3.1	Provide the ability for the PHR Account Holder to enter personally sourced data and to make it available electronically to authorized health care provider(s) or other authorized users or applications.
User Authentication	PHR, external services	To allow proper user authentication	PH.1.1	Unambiguously identify the PHR Account Holder; correctly link the information with the PHR Account Holder and vice-versa.
User Management	PHR, external services	To enables effective management for the administrator (role definitions etc).	PH.3.5.3	Each individual that accesses the PHR should be registered in a directory with his or her contact information and granted specific access rights.
Vaccinations/ Immunizations	PHR, EHR	Dates and types of (childhood) vaccinations	PH.2.5.5	Manage the Account Holder's immunization data and associated capabilities including reminders, alerts, compliance, and administration.
Vital Signs	PHR	For recording vital signs such as pulse, temperature etc. and related information (date, unit etc.).	PH.3.1.1	Provide the ability for the PHR Account Holder to enter personally sourced data and to make it available electronically to authorized health care provider(s) or other authorized users or applications.

In order to address the need for an interoperable and adaptable PHR, the ICS PHR system is expanded to include modules such as home care services, connection to wellness applications to automate input of data (e.g. steps/ day, water/ day, sleep patterns and others), links to the electronic health record of the citizen, the national e-prescription service, and other connections to third party apps for accessing data from clinical/ hospital information systems. In addition, PHR-C is incorporating various personalized medicine modules to address emerging new data, including genetic information, medical advice and recommendations, and prevention information. Specialized modules based on specific chronic conditions are under development to support patient empowerment and self-management. Home monitoring, enhanced communication with health providers, and information on guidelines for prevention and life style have been shown to reduce comorbidities and improve quality of life.

In addition, the experience accumulated and the tools developed during the EU projects (Section 2.3) have rendered PHR-C as an important tool not only for health management but also for clinical research. Advance work in progress includes modules that allow authorized end-users to make cohort analysis on all patient data, to visualize graphically the psycho-emotional profile of patients using various graphical paradigms, to perform advanced searches in specialized databases using natural language (advanced search engine tools), and to allow researchers to generate requests for specific cohorts. Finally, the PHR-C incorporates advanced decision support functionalities exploiting computer-based clinical guidelines.

The use of the PHR-S FM allows the direct linking of the core functionality modules of PHR-C with PHR-S FM Personal Health Functions. Setting conformance criteria will require the definition of certain functional profiles. In addition to the importance of designing a PHR in accordance to the functional models methodology discussed in Section 2.2, it is also vital to be able to provide disease-specific modules in order to deal with the plethora of information needed by the experts/ decision makers who play a vital role in the management of diverse diseases.

4 Conclusions

The real goals underlying the development and implementation of electronic health systems are to allow citizens to stay healthy, effectively manage chronic conditions, reduce comorbidities and improve quality of life. The PHR has the potential to become the life-long companion of citizens that can truly transform health care and establish continuity of care. PHRs offer the potential to improve patient-clinician interactions, empower citizens to become co-producers of their health, and reduce the cost of healthcare by maximizing on-line interactions and avoiding unnecessary hospitals visits. The vision is to achieve a better health service for all citizens and a better outcome for patients. In order to do that any PHR solutions must be prepared for future integration with any health information system. Therefore any information and communication technology support needs to consider current technology developments and demonstrate flexibility and capacity, by adopting related international standards and architectures in a coordinated manner.

As discussed earlier, PHR adoption has been slow due to various reasons such as lack of interoperability, low usability and adaptability and limited added-value [30]. Lack of wider acceptance and fragmentation in efforts remain obstacles for wider adoption and consequently all the expected benefits are yet to be experienced. However, there are success stories to present as a proof of concept. In Australia, almost 20% of the country's population has registered for My Health Record (https://myhealthrecord.gov.au/). This success story indicates that the vision of PHR is indeed feasible under strict regulatory strategies; however, they require strong governmental persistence. In Europe, the key issue to success is standardization, in terms of functionality offering and interoperability, requiring a coordinated governance framework and process.

Following a structured development of PHR using common established set of criteria and functionalities can help the wider adoption of PHR systems. The PHR-S FM offers a realistic and applicable promotion of functionality and interoperability components of PHR systems based on functional profiles. This in turn gives the opportunity to support PHR system certification programs underway or emerging in many countries. Focusing on solving actual end-user needs can lead to a wider adoption and meaningful use of PHR systems. Using the notion of functional profiles, a general purpose PHR can be instantiated for specific types of diseases and the individual needs of the citizens. Adaptability and personalization are key to the successful deployment of any large-scale PHR infrastructure, bearing in mind that interoperability is not possible without standards and specifications.

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