Employing Personal Health Records for Population Health Management

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Abstract. Linking various sources of medical data provides a wealth of data to researchers. Trends in society, however, have raised privacy concerns, leading to an increasing awareness of the value of data and data ownership. Personal Health Records address this concern by explicitly giving ownership of data to the patient and enabling the patient to choose whom to provide access to their data. We explored whether this paradigm still allows for population health management, including data analysis of large samples of patients, and built a working prototype to demonstrate this functionality. The creation and application of a readmission risk model for cardiac patients was used as carrier application to illustrate the functionality of our prototype platform.

Keywords: Personal Health Records, Population Health Management

1 Introduction

Modern technology more and more enables gathering, storage and coupling of various datasets. Telecom providers store usage and location of mobile phones that we carry all day, internet companies store and analyze patterns of web usage, banks are using spending patterns for targeted advertisements, and there are many more examples. By coupling such databases, even more rich information can be obtained, which can be used to our advantage, however, privacy concerns are becoming more and more apparent [1,2]. While some applications can be rather harmless, concerns are more serious when health related data are involved. Coupling various sources of healthcare data, such as hospital information systems, healthcare insurance data, home monitoring devices, general practitioner databases, etc. may enable more precise and personalized care, at lower cost. Unsurprisingly, concerns about ownership and privacy of health data do exist [3]. In most current healthcare information systems, the gatherer of the data, e.g., a hospital, insurance company or GP is considered the owner of the data. More and more people become aware of the value of their data and would like to have additional control of the access to their personal data. Personal Health Records (PHR) meet this need and aim at collecting healthcare data from these various sources, whilst empowering the patient as the owner of the data to decide who to give an authorization to have access to his/her data [4].

In the PHR model, the patient is the only stakeholder with access to the full and holistic overview of the data. This allows for richer data analysis than in current health care data models. To that end, it is important to be able to analyze data form multiple patients. The decentralized ownership in PHRs, however, makes it more difficult to collect such a dataset. Currently, PHRs do not provide a solution to this problem.

We studied options for using PHR data for such research purposes, whilst maintaining the PHR philosophy of empowering the patient. We created a working prototype framework, which we termed an intelligent PHR, which runs on top of Microsoft HealthVault [5] and can apply implemented services on the available data. Examples of such services are statistical analysis methods to perform descriptive or predictive analysis, or the application of developed predictive models. We developed predictive risk models using a dataset of cardiac patients. These risk models were implemented in the intelligent PHR to demonstrate its functionality and can be used for both personal and population level risk prediction using PHR data.

In the remainder of this paper, we will first describe the state of art with respect to PHRs and reveal how the care for cardiac patients can benefit from PHRs after which the methods used to develop the system on top of an existing PHR are presented, followed by its architecture. The paper concludes with a brief discussion and conclusion.

2 Personal Health Records

A PHR is a system of health-related information of a patient, which is managed, shared and controlled by the patient (rather than individual care providers). It contains data from various sources: e.g., clinical data measured by a health care organization, but also home monitoring data, measured by patients themselves. It is a form of an EHR (Electronic Health Record), but, in contrast to traditional EHRs, PHRs are not hosted and managed by a health care organization, but managed by patients. That is, a PHR is accessible online by the patients and by anyone they specifically gave consent to access their information. Therefore, it has the potential to collect a richer dataset by enabling the collection, monitoring and organization of health data on a daily basis, and sharing and querying health and personal information [6]. The information collected in a PHR might include: personal information of the patient, lab results, symptoms, vitals, exercise and dietary habits, health goals (such as to stop smoking) and data from devices (such as electronic weight scales).

Another important difference is that PHRs are aimed not only for patients in a clinical context, as EHRs are typically focused on, but also for (former) patients in other contexts as well as healthy individuals. Hence, PHRs also allow individuals to manage their health and wellbeing by monitoring appropriate vital signs. A particular group of interest is chronic patients, who after an acute phase during which they receive intensive medical care, enter a period of chronic care including self-care which involves close self-monitoring of their condition. To provide pro-active longitudinal care, predictive models that assess future care needs may be of use. In the following we will elaborate why PHRs are particularly interesting for chronic patients, and in particular for cardiac patients.

There are several PHR systems available, including My HealtheVet, MyChart, My Health Manager, Microsoft HealthVault, Health Space, Dossia, Tolven. Out of these, we selected Microsoft HealthVault [5]. Microsoft launched HealthVault, as an interconnected PHR system, in October 2007 in the United States and nowadays is available also in United Kingdom, Canada and Germany. It is defined as a "Cloud-based platform designed to put people in control of their health data" and enables its users to manage their own PHR and was designed to put the users in full control of their health data. Patient level services can be implemented in HealthVault, but the platform currently does not support population level applications and analyses.

2.1 Datasets for Cardiac patients

Chronic diseases become increasingly prevalent in Western populations; illustrated by the fact that for example 49% of the US population in 2005 had at least one chronic condition [7]. Cardiac conditions form one of the most prevalent chronic diseases and are characterized by high mortality and readmission rates. In 2009, 30-day readmission rates in the US were 17.1% after a heart attack, with average costs of rehospitalization of $13,200 [8].

Care for these patients involves a plurality of aspects, including medical interventions, medication, daily monitoring of vitals, regular follow-up checks, but also lifestyle and dietary changes. For this reason, there are many stakeholders involved and lots of different places where data is gathered. One central place where data is contained could really benefit the care for these cardiac patients. In addition, especially when lifestyle and dietary changes are required, patient engagement is key to success. By giving patients a central role in their health data management, PHRs have the ability to further motivate patients to engage in their health management.

Although the quality of care for patients with cardiac conditions has made enormous progress over the past decades, cardiac patients are still often admitted to the hospital [9, 10], with even higher rates for heart attack patients [11], which triggered research of predictive risk models [12, 13, 14]. With such predictive risk models, it is possible to predict adverse events in an early stage and thereby enable early intervention before a costly adverse event happens. It is believed that many readmissions can be prevented by better (planned) care as well as an earlier detection of the onset of worsening symptoms [9, 10, 15]. The research on such models is still in an exploratory phase, and will therefore benefit from the collection of as much data as possible through PHRs. In the framework that we propose on top of PHRs, the development of new risk models and the application of existing risk models can be seen as examples of services that require input data from at least one patient.

3 Methods

The design process we followed for the development of a system on top of a PHR to enable population based management within the PHR paradigm consists of the following steps. First we defined the stakeholders involved in using the system. Second, we created use cases, and third, we designed the architecture of the system. In order to present its functionality, we also created and applied risk models to our cardiac dataset. As part of the initiation of the design process, we sketched the context in which the intelligent PHR would be implemented. Furthermore, we needed to understand usage of the system.

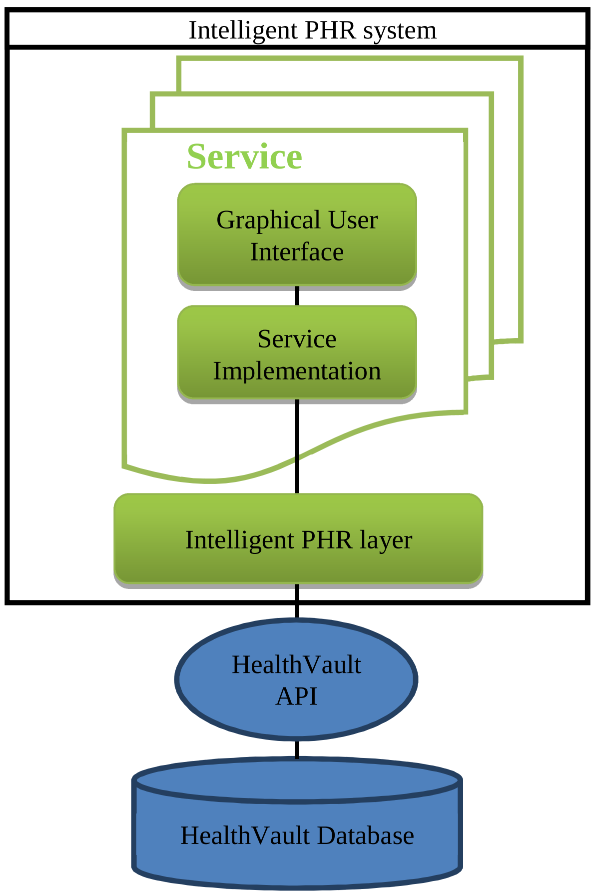

Fig. 1. High level architecture of the intelligent PHR system

3.1 Implementation context of the intelligent PHR system

The aim of the intelligent PHR system is to enable services to make use of Microsoft HealthVault on a population level. Therefore, the intention of the system is to extend the functionality of Microsoft HealthVault while maintaining the philosophy of PHR that patients are in charge of their data. These services will make use of data obtained through the HealthVault API. Microsoft HealthVault allows the retrieval of information at real time, such that there is no need for a local storage in the intelligent PHR. This high level architecture is depicted in Figure 1.

3.2 Usage of the intelligent PHR system

With the intention of finding a solution for the problem we stated, we should mainly focus on the needs and the unmet demands of the stakeholders. The stakeholders that have the greatest effect as well as the biggest benefit from the improvement and adoption of the PHR systems are patients, health workers and researchers.

Patients are motivated to use these systems mainly because they are in personal control of their health. Using a PHR system, they can manage their lifelong health information and their chronic diseases together with their care givers, and also their health can be easily monitored by their family. The need of continuous communication with their care givers, not only in the hospital but also at home, has an essential role in the prevention of the readmissions and worsening of their health conditions.

Health workers are focused on providing the best care to patients while minimizing costs. Using the available applications in the PHR system, they can support their patients' care by monitoring clinical and laboratory data in their PHR record. Online consultations, scheduling and medication refill are benefits that can lead to better health condition of the patients, reduced readmission rates and thereby reduced healthcare costs.

Researchers are interested in analyzing population level data and the development of predictive models which can be applied by patients and health workers. By predicting adverse events using risk models, early intervention can be done to reduce the impact of adverse events or ultimately perhaps prevent them.

In order to design an intelligent PHR system we created use cases based on the needs of these three stakeholders for using services during or after the hospitalization of the patient. These use cases describe the usage of the services in the intelligent PHR system. The difference in the usage depends on the actors in the use cases and where they can use the services. These services may range from generic data inference services to specific risk models. As an example service in our system, we focused on risk model services. We also took into account that patients can be in different care locations (e.g., in the hospital or at home) while using the system, posing different requirements to the system.

First, a cardiologist, during hospitalization of a patient, wants to be able to evaluate the outcome of a single or compare multiple risk models using the PHR of the patient. These risk models can be of great help for the cardiology department to stratify patients, since many undesirable events can be prevented by delivering additional care and support to those at high risk for an early adverse event.

Second, the risk models can not only be used in hospital, but also during care at home. After the patient is dismissed from the hospital, the same functionalities at home are available to health workers involved, in order to prevent adverse events that can occur to the patient. Furthermore, after dismissing the patients from hospital, the patients can take better care of themselves by evaluating the results of the risk models that are calculated by the health worker. For example, the awareness of being at high risk for a hospitalization may help to adhere to lifestyle changes or support therapy adherence. In Section 4 we will elaborate the most important use cases of applying a service, such as the application of a risk model, to a set of patients.

3.3 Development of an example service

As an example service, we will create and apply risk models for the prediction of readmission within one year from hospitalization for ACS patients. For that purpose, we used a dataset that contained a variety of features including demographics, medical history, medication usage, vitals, and lab values. We performed feature selection using Paired t-tests [16] to identify which features distinguish readmission from no-readmission to enough extent. We applied a liberal threshold to the significance level (p-value < 0.4) found in the test to include all the features with a lower p-value than the threshold as input in our risk model. The features were normalized using z-score normalization before applying a machine learning techniques to develop a classifier. To that end, we trained models using two different types of Learning Vector Quantization (LVQ) algorithms, namely Generalized LVQ (GLVQ) and Robust Soft LVQ (RSLVQ) [17]. This type of classifier uses prototypes that are defined in the original data space to represent the classes, which allows inspection and interpretation of the knowledge gained by the classifier in terms of the original data space. We used one prototype per class, and used 10-fold cross validation to estimate generalization performance, measured by accuracy.

To the best of our knowledge, no readmission risk models have been developed for ACS patients, however there are a limited number of mortality risk models. Analogue to the approach by Auble et al., who benchmarked against heart failure risk models that were designed for readmission to predict mortality instead [18], we used the Thrombolysis in Myocardial Infarction (TIMI) STEMI model [19] as a reference.

4 Results

We created an intelligent PHR system that allows patients and care givers to make use of PHRs in Microsoft HealthVault, by applying smart services to the data. The architecture provides the bridge between the PHRs and any service that uses data from the PHRs. The architecture enables the patients to manage their health information, and allows selected care givers to access this information and communicate with the patient. It uses proven means to access selected information in a secure and privacy preserving way. Having built this architecture, the usage of intelligent algorithms can be explored, to provide meaningful decision support for clinician and patient.

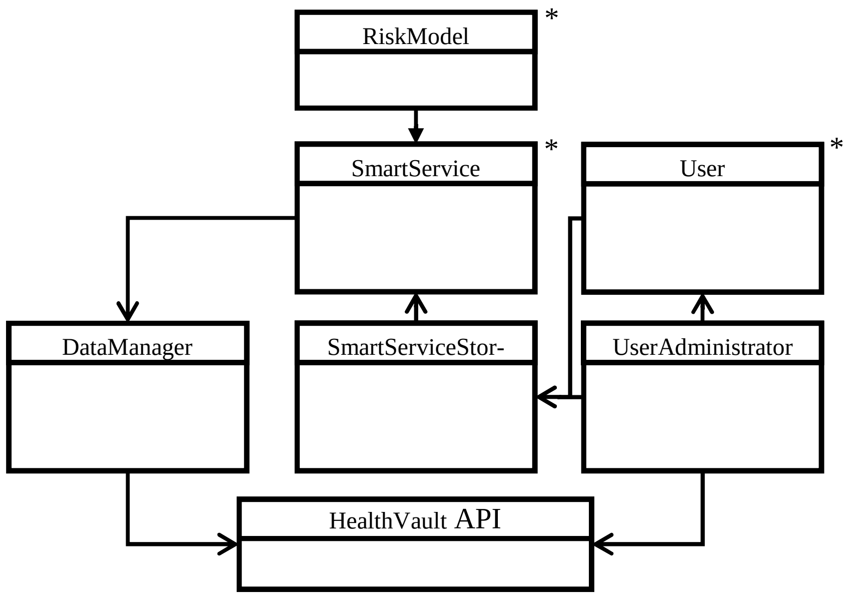

Fig. 2. Architecture of the intelligent PHR system (stars indicate multiply instantiated classes)

The architecture of the intelligent PHR is presented in Figure 2. In order to safeguard the PHR principle of patients being in charge of their own data, we implemented some user management that is required to ensure that only selected (by the patient) users can access a patient's data. The process that includes getting permission from the patient for accessing the necessary data from a user (e.g., care giver) consists of several steps, which are outlined further in the paper using the use case of applying a population level service to data of a set of patients. Given that a healthcare professional has selected a service that he wants to apply to a selected set of patients:

- For each of the patients in the selected set: Get an authorization code from Microsoft HealthVault, by creating a connect request that is based on the patient's ID, friendly name and secret question and answer. Data access is requested for the combination of the particular healthcare professional and selected service.

- Send an email to each selected patient, containing the identity code, a link to Microsoft HealthVault[1] and an information letter on the purpose of the data usage. Via a separate medium (e.g., by phone, traditional mail or a by email to a secondary email address) the secret question and answer are also provided to the patient.

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[1] https://account.healthvault-ppe.com/PatientWelcome.aspx

- Through the opt-in mechanism of Microsoft HealthVault, the patients can now provide authorization through the following steps:
  - Go to the provided link and enter the identity code provided by the application.
  - Enter the secret answer to the required secret question.
  - Select the HealthVault record to be used by the application and authorizes it.
- Periodically check whether the patients completed the authorization. This periodical check is performed, until the patients give consent or until the request expires.
- After the authorization is completed, the intelligent PHR can pass the data in the patient's Microsoft HealthVault record to the service.
- When at least one patient has provided consent, the healthcare professional can apply service to the data of the patients who provided consent. The intelligent PHR sends data requests to each patient, collects the data and applies the service. The result is passed to the healthcare professional using the GUI of the service.

4.1 Example service: Readmission-Risk Model

After applying the feature selection, the following set of features was included in the model:

- Albumin
- Alkaline Phosphatase
- Calcium
- Cholesterol
- Globulin
- Mean Cell Haemoglobin
- Mean Cell Volume
- Red Blood Cell Count
- Troponin I Ultra
- Non-smoking history
- Systolic Blood Pressure
- Diastolic Blood Pressure
- Heart rate
- Grip strength left hand

Based upon these features, several classifiers were trained. Table 1 shows the percentage of correctly classified readmissions in one year using the GLVQ and RSLVQ algorithm in 10-fold cross validation. The performances were better than the reference algorithm. We implemented the predictive models as smart services in the intelligent PHR, which allows the application to individual patients, but also to a set of patients, e.g., to validate the model on another patient sample.

Table 1. The percentage of correctly classified readmissions within one year for ACS patients.

	Accuracy
Reference (TIMI)	65.1%
GLVQ	72.9%
RSLVQ	73.5%

5 Conclusion and Outlook

In this paper we have outlined how PHRs can be beneficial in the care for chronically ill patients, in particular cardiac patients. We identified and implemented a means to allow researchers to use PHRs to perform population level analyses whilst maintaining the PHR philosophy of empowering the patient as owner of his healthcare data deciding who gets access. By doing so, we built upon and maintained the privacy measures taken by PHR providers. We have implemented a working prototype and used data from the cardiac domain to demonstrate its functionality. The developed risk model for readmission of AMI patients was successfully implemented and enables the calculation of patient level risks on a population of patients whose data resides in a PHR. Although we focused on chronic cardiac patients, there the intelligent PHR framework can in principle be used in the care for any other type of patient; however, we foresee most added value for patients with chronic diseases.

In future use of the proposed architecture on top of PHRs we foresee that researchers can provide search criteria along with a consent form to the PHR management system to screen for patients given certain in-/exclusion criteria. The PHR management system can then forward a request for participation with the consent form attached to eligible patients. Then, an opt-in mechanism, as introduced in this paper, can be used to digitally enroll patients in the study. Other topics that require further attention include integration into other PHR systems, preferably using a unified data model such as Resource Description Framework (RDF) [20]. Given that PHR data can come from any source, it would be good to have a label attached to data samples that indicates a confidence level of correctness. Settings this will not be trivial though.

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