A Survey on PHR Technology

James Robison*, Li Bai†, Dimitrios S. Mastrogiannis‡, Chiu C. Tan*, and Jie Wu*
*Department of Computer and Information Sciences, Temple University
{james.robison, cctan, jiewu}@temple.edu
†Department of Electrical and Computer Engineering, Temple University
lbai@temple.edu
‡Department of Obstetrics, Gynecology and Reproductive Sciences, Temple University School of Medicine
dimitrios.mastrogiannis@tuhs.temple.edu

***Abstract*—Personal Health Records are starting to get more attention, as they have the potential to improve the quality of care and reduce healthcare costs. In this paper, the concepts behind PHRs and the advantages of using PHRs compared to other methods of medical record keeping are discussed. In particular, platform style PHRs that allow the easy incorporation of third party tools are examined, as they have the potential to allow medical data to be used in novel ways.**

***Index Terms*—EHR; PHR; Web; Mobile;**

I. Introduction

In the past few decades, electronic health records(EHRs) have started to gain popularity as an alternative to traditional paper-based health records. The basic concept of an EHR is to allow a medical provider to store any medically relevant data they have about a patient in a database of some kind. EHRs evolved from the earlier electronic medical records or EMRs. EMRs were simple, occasionally portable, isolated systems [1]. The more sophisticated EHRs started to offer more features, like the ability to synchronize records to a remote location or provide better ways of presenting the information from the record, for example, collecting certain aspects of the record into a report, or graphing a series of measurements over time. Modern EHRs are networked, both to allow the sharing of medical records among all the providers in a particular health organization, and very often to make records conveniently accessible over the internet [1]. These networked EHRs are of great interest, as they present new possibilities for how to handle medical records.

It is becoming increasingly apparent that reliance on paper records is inflating the cost of healthcare. Paper records are:

- Costly to maintain, as they must be manually updated for every change [2][3]
- Error prone, especially when compared to automatically updated electronic records [3]
- Not portable, paper records are generally less portable between providers and in some cases, like a multi-office practice, even the cost of physically transporting the records can be burdensome [4]

Cost is of great concern with the high levels of medical spending in the US, and using electronic records promises the ability to reduce costs in ways besides just the expense of maintaining paper records [5]. In many cases they are expected to be able to improve the quality of care, and by extension patient health [6]. The providers that have already started using some sort of EHR are generally pleased enough with it that they would not want to switch back to using a paper-based system [7].

While the adoption of electronic record keeping has been slow in the United States so far, usage of it is likely to see a great increase in the coming years. The US federal government has started to take steps to drive the adoption of electronic record keeping among medical providers. Recent legislation, like the HITECH act, provide financial incentives for providers that can show "meaningful use" of electronic records, and in the very near future, will mandate a series of increasing penalties on medicare payments to providers who do not use any electronic records [8].

A new development springing from EHRs are the personal health records, or PHRs. What makes PHRs different is that the patient becomes the custodian of the health record instead of the more traditional model, where a provider or health organization maintains the record on behalf of the patient. Patients have the option of adding information to the record and annotating any existing information in the record, which is typically not the case with EHRs. The patient also has full control over who has access to view or add to the record, unlike EHRs, where the hosting organization controls who can add to or view the record [9].

This paper will first examine and compare EHRs to PHRs and note some of the ways in which PHRs have some advantages over EHRs. After that the next section will describe some key technologies related to PHRs. The section following the technology descriptions will discuss some of the barriers to PHR adoption and future trends with PHRs.

II. Comparing EHRs and PHRs

A. EHR Features

An EHR is simply any computer system designed to store digital copies of medical records. In many cases an EHR will be able to automatically incorporate records from the provider that is hosting it, and possibly other providers that the hosting provider frequently works with. In this manner, it is possible for the EHR to keep up to date with most prescriptions and lab results. Automatic importing helps ensure that the health record stays up to date, and therefore continues to remain useful [10]. Ideally, the mechanism for importing data

would be standardized to make it easy for the medical record to contain data from as many sources as possible [10]. A detailed and complete medical record can reduce or eliminate redundant tests, reduce the likelihood of mistakes, and allows providers to make better informed choices [11].

An EHR may have a number of tools available to it that allow for working with the data. This could include tools to help visualize or graph data, automatic reminders for events like immunizations, or a mechanism to automatically add session data from medical sensors. Some even provide some very limited decision support, like a tool to warn about possible drug interactions based on the patient's prescriptions. When patients are allowed access to the EHR, many simple tasks that would previously have required a doctor or hospital visit, such as prescription refills or medical questions, can be handled remotely saving time and money [5].

B. Limitations of EHRs

While EHRs are an improvement over paper records, they still possess some limitations. Firstly, the extensibility of EHRs is typically fairly-limited, making it difficult or impossible to incorporate more tools to provide decision support or extract data from medical sensors. Certain tools may already be supported, but the restrictions on developing for the EHR may severely constrain which ones can be conveniently used [12]. This reduces the amount of information available in the record, and limits how the information that is available can be used so the record is less valuable than it could be to providers. Any extensions that are created must be specifically customized for a particular PHR, meaning that the cost of any particular extension will be higher [13].

Another problem is that EHRs rarely are capable of getting information from every relevant source. An EHR may lack information from providers that are not associated with that particular EHR. In some cases, patients may not have access to the EHR at all, but even when they do they have limited control over their medical record. As a result, the patient can not contribute any information to the record on their own. For example, if a patient was regularly taking an over the counter medication but lacked the ability to add that information to their record in an EHR, they might not be warned of a potential drug interaction with a prescription medication. This can particularly be a problem if the patient visits a doctor that does not use the patient's EHR [9]. If the patient can not give a new doctor access to their existing records, redundant tests may end up being used. A patient could easily end up with portions of their medical data scattered among multiple EHRs, making it difficult to give a doctor a complete picture of the patient's treatment history [14][15].

This issue of data portability is a major shortcoming of EHRs. An EHR can lose a great deal of utility if the patient chooses to change providers, if the patient moves to another region of the country, or possibly even if the patient changed their health insurance. In cases where the patient has no access to the PHR, even exporting the data may be impractical [2].

C. Device based PHRs

One older variant type of PHR that addresses the portability problem common with EHRs is a device-based PHR that is physically carried by the patient from location to location. They typically consist of a USB flash drive preloaded with some software intended to make organizing medical information more convenient. This type of PHR does give the patient complete control over their medical record and provides much greater portability, but is very limited in functionality [16].

They typically have no mechanism for automatically updating with lab results, provider records, prescriptions, or interfacing with medical devices. With all updating done manually, they can become out of date very easily, which reduces the value of the system and can result in it going unused [17]. Manually updating the health records is very time consuming and error prone, which makes stand alone systems even more undesirable [17]. Isolated PHRs by their nature must depend on patient entered information, which means only the PHRs of the most motivated patients will remain up to date, and providers may not feel that they can trust the records to be accurate due to limitations of the patient's health literacy [9]. Patients have also been found to express unease with the idea of entering all of their own health data for fear that mistakes or misleading additions could damage the usefulness of the health record, a sentiment echoed by providers [18].

These devices do meet the goal of making the patient's record more portable to an extent, but lack the easy access that would be provided by a web based PHR. Due to their offline nature, they can not provide patients a mechanism to communicate with their doctors. They do not offer any sort of decision support. Since they are not easily extensible, it would be difficult to integrate any tools for decision support or make use of medical sensors [16]. In addition to their limited functionality, they can pose a security risk. If the device is lost, the patient's medical record can be completely exposed. If the device were to be infected with malware it would be a threat to any provider computer it was connected to [19].

D. Networked PHRs

Networked PHRs are of much greater interest than stand alone systems, as it is only the networked systems that have the potential to change the way health data is used. With isolated systems like the portable PHRs, there is a danger of each system containing only a subset of the data, greatly limiting their value [9]. A networked PHR allows for the possibility of providers contributing to the health record directly, or for the PHR to import data automatically from the one or more provider EHRs.

With a typical EHR, or relying on paper based records, patients can feel excluded from access to their health records. Making the patient the custodian of their own health record makes them feel more involved in the maintenance of their health [18]. Providers who are early adopters of the technology have found the feeling of empowerment patients feel is very helpful [10]. Some physicians feel use of PHRs can strengthen doctor-patient relationships [20]. Since the health record is

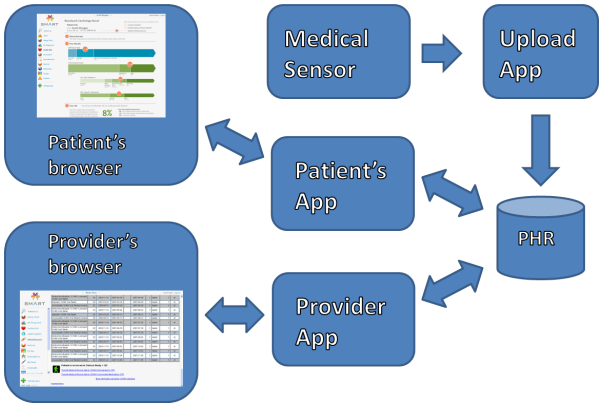

Fig. 1. Simplified platform style PHR flow

tied to the patient instead of a particular provider, a patient can continue to use it even if they switch providers for some reason. This makes the record more valuable to the patient, giving them more motivation to use it and keep it updated which in turn makes it more valuable to providers. It even provides an opportunity for patients to include extra annotations that would not normally be recorded, which could be of personal benefit to the patient as they track their own health progress, or possibly help give a provider a more complete picture of the patient's state. Involved patients are more likely to take the effort to help maintain their health record. A stronger feeling of investment can translate into better health behaviors, and better adherence to treatment schedules. Some PHRs even have social features that help to encourage good health practices [17]. Smoking cessation and maintaining blood sugar levels are two frequently given examples of health behaviors that can be affected in this way. Letting patients with chronic conditions see their progress over time is particularly helpful in improving health behaviors.

E. Platform style PHRs

In many ways platform PHRs resemble the model adopted by Facebook or Apple's iOS. The PHR acts as a repository for the patient's health data, while allowing it to be shared and manipulated by any .apps. that are approved by the PHR and selected by the user. These .apps. are small interchangeable pieces of software that can either be provided by the PHR or a third party. Each app provides a single function or narrow range of functions with larger variety provided by having a selection of apps [13]. Some of the functions provided by apps might be assisting with maintaining the patient's health record by importing data from external sources or providing a more convenient interface for the manual input of data, keeping track of appointment or vaccination schedules, providing reminders to take prescription medications, or helping the patient visualize and understand lab test results [13].

A simplified flow of how apps interact with the PHR and with users is shown in fig. 1. In this diagram, the patient is using one app to view their medical record while a researcher or doctor is using an entirely different app to view the same data in different manner. At the same time, the upload app has no interface at all while it adds data recorded from a medical device to the record automatically. Fig. 2 shows a sample app that helps a patient understand the significance of their cholesterol levels, and how that app displays within the interface of the hosting PHR. The area overlaid in blue is the interface directly to the PHR while the inset box displays the interface from the externally-hosted app.

Many other applications exist, and with the possibility for third party developers to produce more, there will be a large number of ways for users to take advantage of this platform model to add value to their health records. An essential component of this strategy is that the individual apps should be replaceable, unlike the components of a more traditional EHR or non-platform PHR with fixed components [12]. The user still has to commit to a particular PHR platform, but is not committed to a particular set of tools, as would be the case with older PHRs/EHRs. This creates an environment where app developers will compete with each other in terms of functionality and price [12][13]. This competition again increases the value of of the user.s record as they are able to take advantage of the best of the resulting apps.

III. Key Technologies

A. Indivo X

A typical PHR serves as a repository for patients' health information but does little else. As platform PHRs can be expanded to provide decision support, they are of much greater interest. As an example of a modern platform style PHR system, we can look at Indivo X. Indivo X is a freely available, professionally developed, open source set of software for setting up a PHR service. It has all the major features that one might hope to see in a PHR, including supporting the use of third party applications that integrate with the health record server. It allows patients to add any documents they feel may be relevant and add as many annotations to their records as they care to, but disallows editing of records that were contributed by providers. In this way, a doctor viewing the patient's record can be confident that, for example, a lab report that is included in the record was not altered by

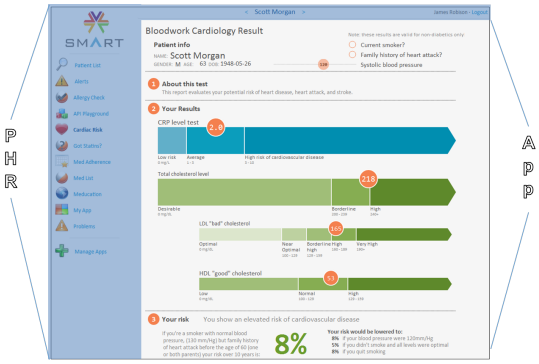

Fig. 2. Sample PHR app interface

the patient [21]. As a consequence of it being open source, an indivo instance can easily be created and customized for research purposes. Indivo X serves as the foundation of several PHR services in use by actual patients and providers, and is still actively being developed [22][21].

So far most Indivo deployments have been for research purposes, but there are a few instances where it is used by patients. The MyOSCAR PHR is an open source PHR based on the Indivo code base that was developed by McMaster University. It integrates with their EMR OSCAR electronic medical record site and is usable by patients [21]. Unfortunately, it is based on the Indivo 3.0 code which predates Indivo X and thus, lacks the platform model style features that were added to the more recent releases. For an example of a fully featured platform PHR, in use by actual patients, we can look at the Dossia PHR. Indivo X is the foundation of the Dossia PHR service, which is one of the largest PHR services in the US. It boasts a thriving application market with a large selection of tools available, some hosted by Dossia, and others external [22].

B. Security

In order to enable integration of third party applications, it is vital that there exists a mechanism for the applications to access the medical data without compromising the user's own authentication information or exposing any medical information publicly. If the user's own credentials were shared with an application, it would be possible for the application to access more than was intended, and it would make it difficult to revoke access to applications that were no longer wanted. If the user were instead forced to create a separate set of credentials for each external application they wanted to use, the user experience is greatly diminished, discouraging users from using more than a very small number of tools [23].

To solve this problem, the OAuth protocol can be used. OAuth is an open standard that allows for a web service or application to request a resource without having any knowledge of the resource owner's credentials. The site that hosts the resource contacts the owner directly so the owner only has to give their credentials directly to the resource host in order to approve the access request for the resource. The requesting web application is then given a unique token that allows it limited access to the resource. The fact that the access token is unique makes it easy to limit what resources are accessible to the web application, and revoke access manually or based on a time limit [24]. More information about OAuth can be found in the protocol specification [25][26].

C. Integration

To further increase the value of a platform PHR and also to bring development costs down even more, it would be helpful to have a common standard for PHR applications. For this reason, the SMART platform is being developed. If an application developer were to develop a really great application that uses a patient's blood work to assess their risk of having a heart attack using the SMART platform, that application could then be used with any PHR that uses the SMART platform with no additional modification [13]. Without a system like the SMART platform, that application would have to be modified or even completely rewritten for every PHR the developer wanted the application to be usable with, wasting time and money [13].

Any EHR or PHR that wants to support the addition of third party applications can build a SMART container that implements the SMART API. The container serves as a common interface for all SMART applications. Any application author can then write a SMART application using the SMART API and it will work with any and all EHRs and PHRs that implement a SMART container. The SMART container handles all the work of converting the medical data into common formats. Since it provides a common interface even though each EHR/PHR could be very different internally application developers can write an application once and have it be usable with every EHR/PHR that implements a SMART container. Since this makes application development much faster and cheaper it promotes an environment where there will be a larger amount of applications and thus more competition between applications. The expectation is that the competition will help drive down costs and provide more utility to users [13][12].

A side effect of using the platform model is pressure towards adoption of common or open standards for health data. Each PHR will need to convert health data into a single format so that it can easily be manipulated by any apps intended for that PHR. If a small number of platforms come to dominate the PHR market, as has already happened in the smartphone market(iOS, Android), or the online social network market(Facebook), there would likely be a small number of dominant formats. This seems to already be occurring: many PHRs are allowing medical records to be exported in either CCR or CCD format, and are using standardized systems for encoding medical information like LOINC and SNOMED CT. As more platforms adopt the same common standards, it makes it increasingly easy for developers to target multiple platforms with their software, as well as making it easier for providers to interface with PHRs to store or retrieve medical data. There are even efforts underway to provide a universal app interface to platform style PHRs to allow app developers to write an app once and have it available to many platforms. This is a great benefit to the platforms as it increases the number of competing apps available to them, to developers as they can expand their potential market with little to no additional development cost, and to users who will have access to a larger selection of apps.

D. Personal Health Applications

Here, several personal health applications(PHAs) of the type that are used with a platform style PHR are described. They highlight some of the advantages of platform style PHRs.

A PHA designed for parents of children with attention-deficit hyperactivity/disorder was developed at the Boston Children's Hospital[27]. It was designed to allow for information about the child's symptoms and medication to be entered

by the parent directly into a PHR without the need to rely on filling out a series of paper forms provided by their doctor. While they did have some issues with the computer skills of their test users, the usability tests they performed allowed the final version of their application to collect more information than the traditional paper forms. Several steps were taken to overcome problems faced by their test users. They integrated tutorial videos into the application, they adjusted the language of the application to account for the limited health literacy possessed by most of the testers, and when the user submitted information, the application would prompt them again for any skipped questions.

A group at InterComponentWare incorporated developed a personal health application to help patients with diabetes to track their condition[28]. The application was specifically designed to be attractive to users, so as to encourage patients to regularly update their medical record with information like weight and glucose measurements. It includes several "fun" features, like slider bars that fill with color as the user interacts with the application. Patients are also given the option to select health targets for themselves for actions like exercise and taking medication. The application will then track their progress towards completion as the user continues to enter information into it. In addition to making it easier for a patient to keep their medical record updated, this demonstrates how a PHA can help improve health behaviors.

A PHA called TrialX was developed to help match patients with relevant clinical trials based on the patient's pre-existing medical conditions[29]. Every patient that opts to use the TrialX PHA can view a custom list of medical trials based on the patient's demographics and medical records. Details are given about why each trial was suggested to the patient, and the patient is given the option to fine tune the search results to more easily find the trials that interest them. By making it easy for patients to be matched with clinical trials, enrollment should see an increase. This is good for patients who are in need of additional treatment options, and facilitates medical research. As the number of TrialX users increases, the developers hope that it will be possible to take advantage of anonymized usage statistics for epidemiology research. For example, finding trends that associate a particular medical condition with a demographic group or geographic area.

IV. Additional discussion

Here we will discuss some remaining issues that have slowed adoption of PHRs in particular, and EHRs in general. Cost can be a major concern with switching to an EHR or PHR. There is a substantial setup cost implicit in first starting to use one. That said, most EHRs are expected to reach the break even point on cost within a few years and to actually show a benefit, with regards to cost, after that. The one notable exception is with provider-tethered EHRs, which are not expected to reach the break even point in under ten years [5]. Benefits in quality of care might make such a setup worth considering even given the cost, but it would require very careful consideration. Aside from just the monetary setup costs, many providers have expressed concern about the loss of productivity due to the adjustment to using a new system. This can especially be an issue with health care personnel that are not as computer-savvy [3].

Adjusting to the new system can be an issue for patients as well. One of the biggest barriers to patient adoption of PHRs is usability [15][30][31]. Patients will frequently have limited technical skills, and even more limited medical literacy, which can impair their ability to make use of a PHR unless the PHR is well designed to accommodate its user's limitations. Poor usability can result in incomplete or misleading data being added to the health record by patients, the prospect of which makes providers hesitant to switch over. These same usability issues can even reduce patient privacy. In trials, many patients would divulge their personal credentials to others in order to get technical assistance, due to problems understanding and using the system [18]. Privacy needs to be carefully considered when switching over. One of the greatest benefits of EHRs and PHRs is how much more easily medical records can be accessed and shared, the flip side of that is it becomes more difficult to safeguard patient privacy [3]. The issue of limited health literacy among patients is also of great concern to providers. Providers fear that patients may become unduly alarmed by medical results they do not understand. Abnormal test results could especially cause great distress [20]. Some physicians are concerned that this could increase their workload, as they may have to spend extra time answering questions and educating the patient about the meaning of information in the health record [3].

Legal liability is of great concern. Providers are accustomed to divulging as little information as possible to patients, which helps protect them from possible future lawsuits. With all the medical data in the hands of patients, there is much more potential evidence which could be brought to bear, and it becomes much easier to compare and evaluate different providers. The level of scrutiny providers are subjected to is new and can be uncomfortable for some [3]. A greater legal risk is from problems resulting from treatment based on patient provided or edited information in the health record. Providers are concerned about liability for problems stemming from using incorrect or incomplete data from patients [3].

V. Conclusion

PHRs and especially platform style PHRs could have a very positive effect on healthcare if they were to see widespread use. The cost savings alone make the prospect very appealing, not to mention the potential for improved quality of care.

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