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Empowering Patients through Personal Health Records: A Survey of Existing Third-Party Web-Based PHR Products

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Abstract
Empowering people to play an active role in their own healthcare influences their health state positively. PHRs' features and functions are key factors for the empowerment of patients, but only little research has been done to date. This survey identifies PHR functions and properties that are relevant for patient empowerment and compiles a list of PHR products that are currently available on the market. Based on a literature review and former research work, a function taxonomy checklist including 6 domains and 58 subgroups of features was created. A list of products was compiled from two public directories that list PHRs and from the result of an explorative search that was performed utilizing various search engines. Together with the PHRs found during the scientific literature review this lead to an adjusted list of 48 products. Every product was analyzed by the usage of a questionnaire, that was sent to the product vendor, the public available information about the product, and whenever possible by the exploratory use of provided test accounts. There has been good support for most of the common features in the structured data, services, security and interface domain, whereas almost none of the PHRs use existing medical standards for the storage and communication of their data. At the present time, PHRs have implemented only basic features allowing only basic patient empowerment. The breakthrough for empowerment will require cost intensive implementations of medical standards to provide interoperability and health services which let the users make a choice for the usage of a PHR.

Keywords: Personal Health Records; Electronic Health Record; Empowerment; Standards; Medical information systems; Medical Computer-Assisted Decision Making; Patient Empowerment

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1 Introduction

The 1996 WHO Ottawa Charter for Health Promotion [1] claims that enabling people to increase control over their health or to cope with the challenges of everyday life is of prime importance. Empowering people to play an active role in their own healthcare influences their health status positively.

Rappaport defines empowerment as a "process by which people, organizations, and communities gain mastery over their affairs" [2], whereas patient empowerment refers to a control of individuals' experience of health or enables patients to be more involved in their healthcare [3]. That is, patient empowerment aims to a process of activities helping "individuals to manage their healthcare and advocate for themselves as they use healthcare services" [4]. Hence, many researchers stated the goal of empowering patients being of prime importance [5, 6, 4] for a potential breakthrough to forming the health system of the 21st century [6].

As an enabling technology, Personal Health Records (PHR) are a key factor in empowering patients [7] and will help them to play an "increasingly central" and active role in their own healthcare, as envisioned by the national consensus conference [4]. Creating PHRs to empower consumers addresses the 10 design rules of the health system of the 21st century [6], as stated by Tang and Lansky [8]. Patient empowerment is an important success factor of at least six of these 10 design rules [9].

Various definitions for PHRs have been proposed [4]. According to Markle Foundation "The Personal Health Record (PHR) is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it" [9]. PHRs are not about separating people from the health systems or their physicians, they are about involved consumers managing their own health information and thus making shared decisions on shared information [4]. In their recent report "The Value of Personal Health Records", the Center for Information Technology Leadership (CITL) has shown the potential economic value of the adoption of PHR systems for patient empowerment [9].

PHRs have the potential to improve the way health systems interact with patients and help physicians to gain a more complete and balanced view of their patients [4]. Surveys suggest that patients want to use PHRs and believe in their value [10]. Nevertheless, in practice many problems about sharing information remain unsolved: Which format is stable enough in time to store data from "cradle to grave"? How have the data to be stored, to enable a processing e.g. for public health or decision support applications? Which concepts could be used to bring the information from a PHR to elderly, handicapped or people with a low level of education? (see [11], [12]). In 2008 Kaelber et.al. stated that "despite widespread interest and activity, little PHR research has been done to date" [10]. Furthermore, a research agenda for PHRs was proposed and it was found that "at this state … PHR function evaluation may be the most important area of PHR research" [10].

Many PHR products are already available on the market. Recently, large technology vendors like Microsoft and Google debuted their PHR products (see: [13] and [14]). PHR architectures can be distinguished according to a number of criteria. In their recent report CITL uses four dimensions – methods of data incorporation, types of data systems, number of data sources, and type of data exchange to distinguish four PHR architectures [10]. This survey focuses on third-party PHRs which aggregate healthcare data for individuals and incorporate data from external sources, without the ability to automatically synchronize data into the medical workflow [9]. Most currently available PHR products fall into this category while interoperable PHRs certainly include the greatest potential for patient empowerment but are not yet available [10].

We examined 48 web-based third-party PHR products comparing their functionality according to a function taxonomy checklist. This taxonomy was designed with special regard to functions required for or at least conducive to patient empowerment. Our goal was to examine how well patient empowerment can be achieved using these currently available products and to give advice for further enhancement.

2 Methods

The core purpose of the survey was to evaluate a representative selection of currently available web-based third-party PHR products with respect to their applicability for patient empowerment.

The survey was conducted from October 2008 to June 2009 according to a three-step methodology which included: Developing a function taxonomy checklist for PHRs with special, but not exclusive regard to patient empowerment, selection of a representative set of available PHR products, and analysis of selected PHR products according to the chosen function taxonomy. It should be noted, that this survey is not intended as a product comparison. Therefore, only summary results are reported.

Function Taxonomy Development

The comparison of PHR products with respect to their applicability for patient empowerment was done using a PHR function taxonomy. Existing taxonomies were found not to be comprehensive enough for the survey's purpose. Kaelber et.al. [9, 10] found 100 unique citations related to PHRs, 19 publications were found to be either related to PHR function description or function evaluation. A complementary PubMed search including publications till October 2008 found another 36 citations. Abstracts of all new publications were reviewed for information related to PHR function description or function evaluation. Overall four additional publications were found to contain relevant information. Relevant publications (overall 23) were distributed within a group of researchers, all with a strong background in the health IT domain, which were also invited to contribute own research results regarding PHR functionality. In three meetings the results of the literature review were discussed resulting in a consolidated function taxonomy checklist (see **Table 1**). Although very similar, the taxonomy depicted in [9] was published after the taxonomy used in this survey had already been developed and the evaluation of available PHR products had already started.

In order to foster patient empowerment, a PHR has to provide functionality for storing and sharing information as well as for interpreting stored information to help making shared decisions. A PHR should respect Markle Foundation's "Seven Patient and Consumer Principles" [7]. Our taxonomy is comprised of six function domains subdivided into overall 58 function subgroups. The "Structured Data*"* domain describes *which information is stored* in a PHR [15]. "Document Formats" comprises options of *how information is stored*. This enables the patient to collect and manage standardized medical documents from health care providers as well as additional content from non-professionals. "Data Protection and Security" reflects essential functionality of a PHR so that the owner holds and may delegate control over the data. The "Services" domain contains function-groups about *how the data is used*. Services such as drug interaction warnings or healthcare education extend the functionality of a PHR and give patients the opportunity to make informed choices about their lifestyle and care. "Interface" allows users to access and use the PHR without being handicapped by technical, cultural, or other barriers. Finally the "Interfaces / Data Exchange" domain describes mechanisms for *exchanging data* with external care providers in the healthcare system [16].

Selection of Products

The selection of relevant web-based third-party PHR products started in November 2008 and took place in a two-step process. First, a list of PHR products was compiled from various scientific and public sources. The initial list was then reviewed, deleting unavailable, duplicate, unmaintained, and unsuitable products.

For the first step we used a list of available PHR products published at [17] as a starting point. In order to identify commercial and scientific oriented products, a search for the term "personal health record" in search engines Google, Yahoo, Sourceforge, and Medline was performed. In each case the first one hundred search results were reviewed by a research assistant in about four weeks and new products were added to the list. In addition, products found in various conference proceedings and medical journals were added to the list. In January 2009 the list of available PHR products contained 71 items.

Within the second step all listed products' websites were visited. Additional products found during the evaluation phase were added until end of May 2009 and led to an overall list of products with 81 items. Products not provided by third parties (e.g. if they are provided directly by an health insurance company), not being web-based, or having no PHR functionality were removed from the list (overall 5 products fell in this category). 8 further products were removed because their websites were complete or in essential parts unavailable for more than five working days (revisited each day). Additionally, 6 products being no longer maintained were removed from the list. 14 products provided not enough information nor a test account to make a reliable statement about their capability to support patient empowerment. We created 32 (≈67 %) accounts by our own, used 7 (≈15 %) demo accounts and found enough information in 9 (≈19 %) cases. The final list of products to be evaluated counted 48 web-based third-party PHR products (see Table 2).

Analysis of Products

The evaluation of listed PHR products was done in a three-step process. First, all providers of products contained in the list of PHR products were contacted electronically either via e-mail or online web-form. By this way a short questionnaire with 8 open questions was sent to them. Mainly, these questions are about functions, which are provided on the application programming interface (API) level and were thus hard to obtain only by usage of the web interface. Providers who did not answer within 2 weeks received a reminder containing the same questionnaire. The questionnaire (see Questionnaire) was based on the developed function taxonomy. 48 questionnaires were sent, 18 returned. 8 of these contained answers with sufficient technical details for the evaluation (response rate ≈17 %). The results were reviewed by a research assistant, who extracted relevant information. Secondly, a 32-week explorative study performed by a research assistant using test accounts and online tutorials provided by PHR providers was conducted. The study included all listed PHR products and gained additional results and partially proved questionnaires' answers. In a third step, a search for complementary material about listed products using search engines like Google and Yahoo was performed.

3 Results

The following section contains the results of the survey mainly in numerical form and describes some function specific characteristics in addition to the function taxonomy, which we obtained during our work.

Structured Data

The “structured data” domain includes all kinds of information stored in separate fields within the PHR. Within our survey we structured available information into 17 different categories, e.g. Medications or Health Insurance Information (see Table 1).

Storage of structured data is very well supported by most PHR products, only few products had limitations in this area. These self-imposed limitations often arise from specialization and focusing on certain diseases (for example diabetes). Over 77% of the products were able to store information about medication, allergies, conditions / symptoms, and vaccinations (see Figure 1). Products mainly differed in how information is entered. Most often the user has to type information into free text fields or select them as an item from a drop down list. Usage of free text fields may be regarded as less comfortable for the user and implies a higher risk of entry failures, especially regarding “Diagnoses” and “Treatment/Procedures” information. Reliability of information entered in these data fields is especially important since they are used for steering functions such as drug interaction or drug - disease interactions checks. Storage of test / laboratory results, health insurance information, and address data of medical contacts e.g. physicians or nurses is supported by most products.

Nearly 40% of all products are capable of storing advance directives or organ donation information. This seems to be a high value, but again products differed in how information is stored. In some products only boolean values, e.g. organ donor status: yes / no, could be stored instead of enabling the user to place detailed information. Storage of scanned

documents seems to be a good compromise and is supported in average of both categories by approximate twelve products. Two products presented a questionnaire to generate a legal document that can be printed and signed by the user.

Some examined solutions addressing the demographic change provide tele-monitoring of vital signs in patients' home environments. Such applications should have the ability to integrate their data into PHRs. We could only identify three PHRs that were able to store data from mobile devices like e.g. pulse monitors. All these products offered applications that the user could install on his own PC to transmit the data to the PHR.

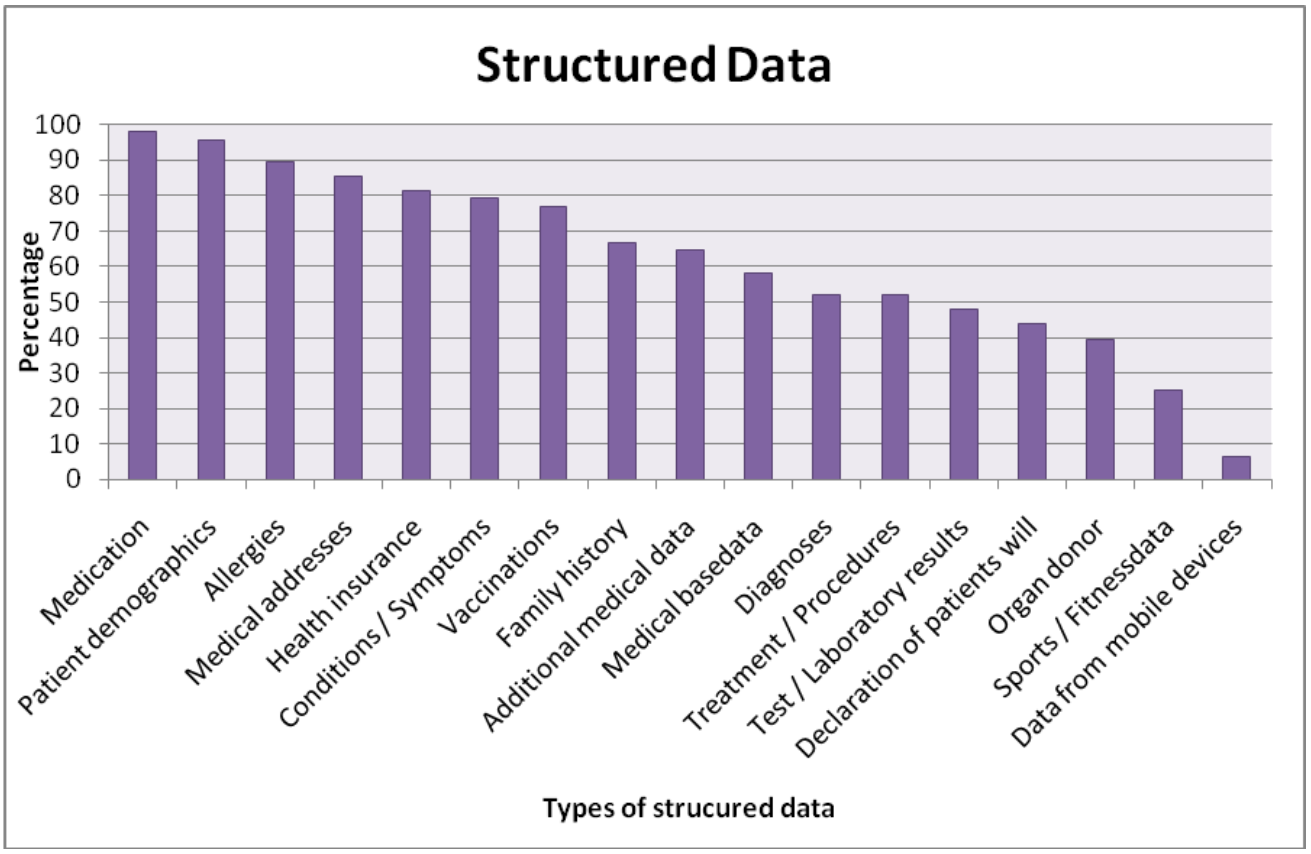

Figure 1: *Percentage support of structured data.*

Services

Various services providing additional value based on the information stored by the PHR products. Within this review we concentrate on the most common and valuable services that were available in at least three products (see Table 1, category "Services").

Information stored within a PHR is highly confidential in nature. Nevertheless, in case of an emergency or when the owner of the PHR is no longer capable of administrating the information on her or his own, information still has to be accessible on behalf of the owner. Support for granting access to the PHR to other persons is summarized within the service category "Management functions for multiple users". Two approaches to realizing this functionality have been found:

- A locum function that enables a second person to gain access or complete control over the data of the PHR user (found in 6 products or ≈13 %), and
- A function that enables the PHR owner to manage multiple users of the electronic health record under his or her account. A popular use case for this scenario is a mother managing the health information for her children (found in 13 products or ≈27 %).

71 % of the PHRs provided some kind of service for accessing stored information in case of an emergency, e.g. while the owner of the PHR is unconscious. One possibility for supporting emergency access is to assemble the most important medical data and provide it on a printed card that fits in a wallet. In some cases emergency login information, e.g. username and password for the PHR, were printed on the card as well. In a few cases the emergency or account information was printed on a bracelet or necklace. Besides the direct emergency access to the PHR, some of the health record maintainers provided possibilities to gain access via phone or fax. Different types of access mechanisms are described in the "Data Protection / IT-security" section below.

Supporting people in managing their medication, e. g by reminding them to take these or generating warnings in case of conflicting prescriptions can provide a significant value for patient empowerment. Within the prescription management category we distinguish two main functions:

- prescription history and current medication (found in 24 products or 50 %) and
- a function for ordering (semi-) automatic refill of medication (found in 14 products or ≈29 %).

A drug interaction check was found in six products (13 %). Four of them performed the check automatically as soon as a new prescription was added. Two products required a manual instruction to perform the check.

The provision of additional medical information on health related topics was found in most PHRs. Products mainly differed on how this information was accessible respectively presented to the user. Five modalities for presenting additional medical information prevailed: personal content retrieval (the user receives information for his or her individual needs), medical library (contains detailed information on diseases), medical encyclopedia (explains medical terminology to non-professionals), health news, and health related tips (see Figure 2).

For most of these modalities there is more than one technique for accessing the medical information. Health news were for example sent by newsletter, E-mail, or RSS feed or they were displayed on a personal homepage within the PHR.

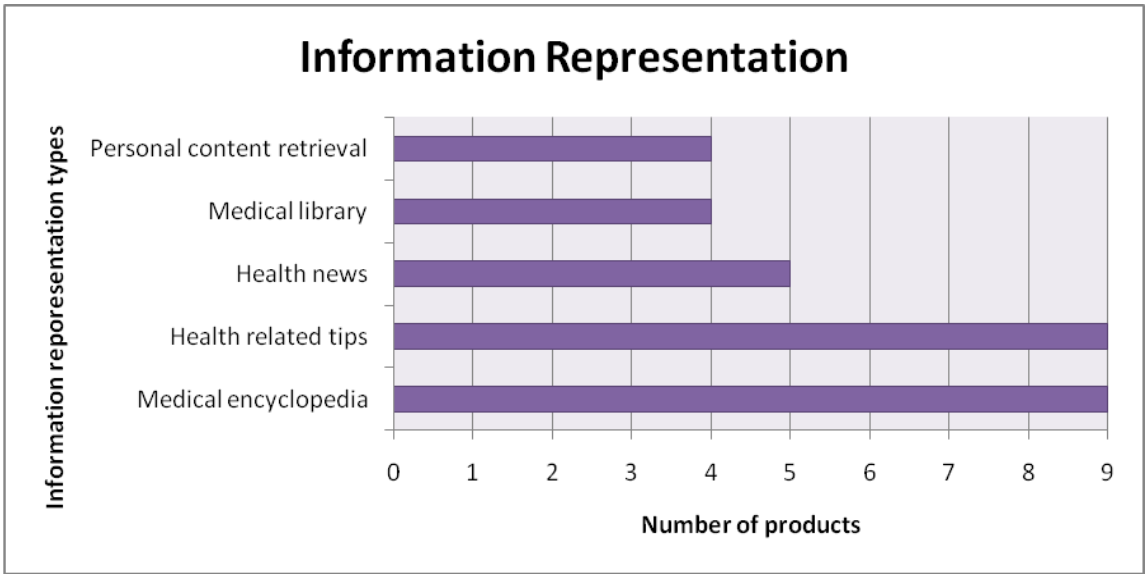

Figure 2: *Absolute number of products supporting different types of health information representations*.

While the aforementioned category "Medical Information" summarized unidirectional presentation of information, enabling a dialog between the PHR users and medical experts is more complicated. The "Professional / Community Information" category summarizes services enabling the users to initiate a bidirectional dialog. Three types of such bidirectional communication were found:

- Messaging with healthcare professionals or health related communities (found in 7 products or ≈15 %)
- Forums in which healthcare professionals or health related communities share knowledge (found in 5 products or ≈10 %)

- Blogs (web logs) listing health related information and the possibility to write a comment (found in 5 products or ≈10 %). Four out of five products offered both, forums and blogs.

The "Administration / Documentation" category summarizes all services helping the user to manage his or her own health by gathering additional information. The examined products supported: Notes (≈33 %), reminders (≈23 %) informing the user about events and often connected with appointments (≈22 %), and calendars (≈13 %) as well as health related diaries (≈8 %). Additionally, overall 23 (≈48 %) of the examined products were able to store arbitrary documents ("File upload for unsupported document types") enabling the users to store any additional information not covered by the aforementioned possibilities.

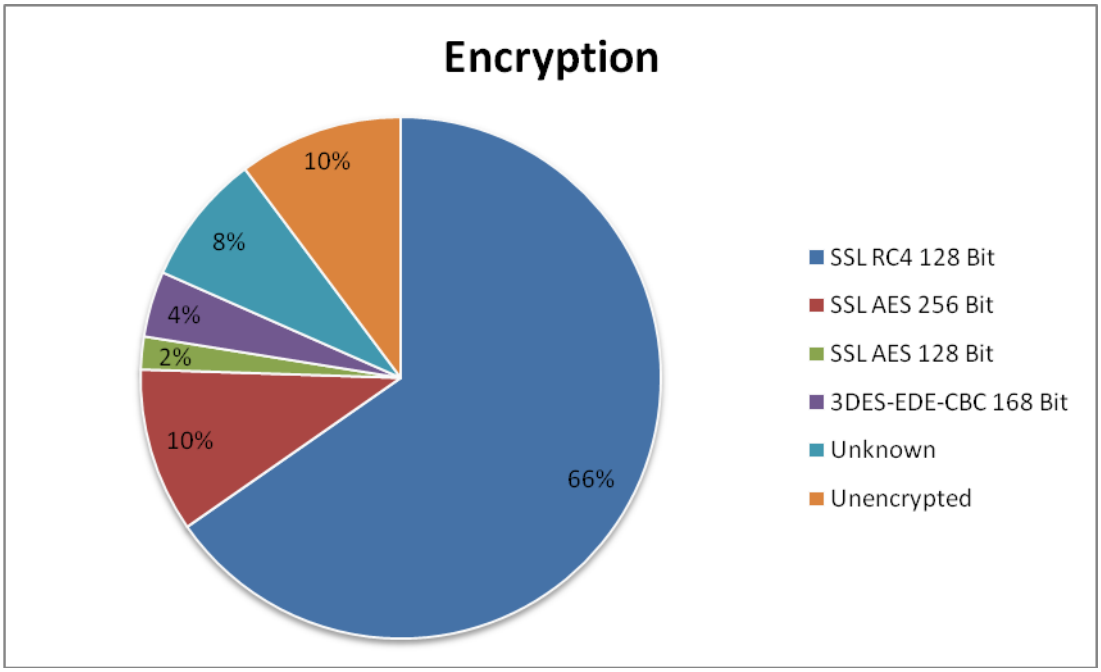

Figure 3: *Distribution of encryption methods.*

Data Protection / IT-security

Data stored with a PHR is private and often considered highly confidential. Therefore, storage of information within and transfer of information into the PHR should be secured. Since we had no access to the security mechanisms used within the servers storing the PHRs, we examined security mechanisms for the transfer of information into the PHRs and relied on answers in the questionnaire regarding encrypted storage of information. Support for encryption of communication between the internet browser and the PHR web server based on standard mechanisms (see Figure 3) was examined with the help of the browsers´ mechanisms for displaying encryption status and type. Widespread usage of encrypted communication was found (in all ≈82 %). In 10 % of all cases encryption techniques were not used and for eight percent we were not able to reliably decide whether it was used or not.

According to the questionnaire and the examination 16 (≈33 %) products supported encrypted data storage. In one case, the encryption key was maintained by the company, for three products the key was maintained by the user. For the remaining 12 products we found no statement on this topic.

In some cases, a PHR owner might have to only partially grant access to her or his PHR, limited either to certain pieces of information or only for limited time windows. Therefore, we evaluated access right types the user could delegate to other persons. 21 (≈44 %) of the products allowed read-only-access, 19 (≈40 %) a read-/write-access and 4 (≈8 %) an update and delete access. The access rights could be assigned with different granularity: In 15 (or ≈31 %) of the PHRs the user could only delegate rights for his whole profile. 10 (or ≈20 %) products allowed the user to delegate rights for categories, which clustered a set of information, e.g. name, forename, and day of birth for the category "Patient demographics". One product allowed delegation of access rights on information level, e.g. "Forename". The easiest way of authentication is usage of cre-

dentials (username/password combinations). Additionally, two PHRs allowed user identification through digital signatures. Four products offered time-based access, mainly with an expiration date for a delegated login. Seven products implemented role assignment, which encapsulates special access rights e.g. for emergency login, physicians, or family members. An audit trail, storing performed operations, accessible by the user was offered by ≈35% of the PHRs.

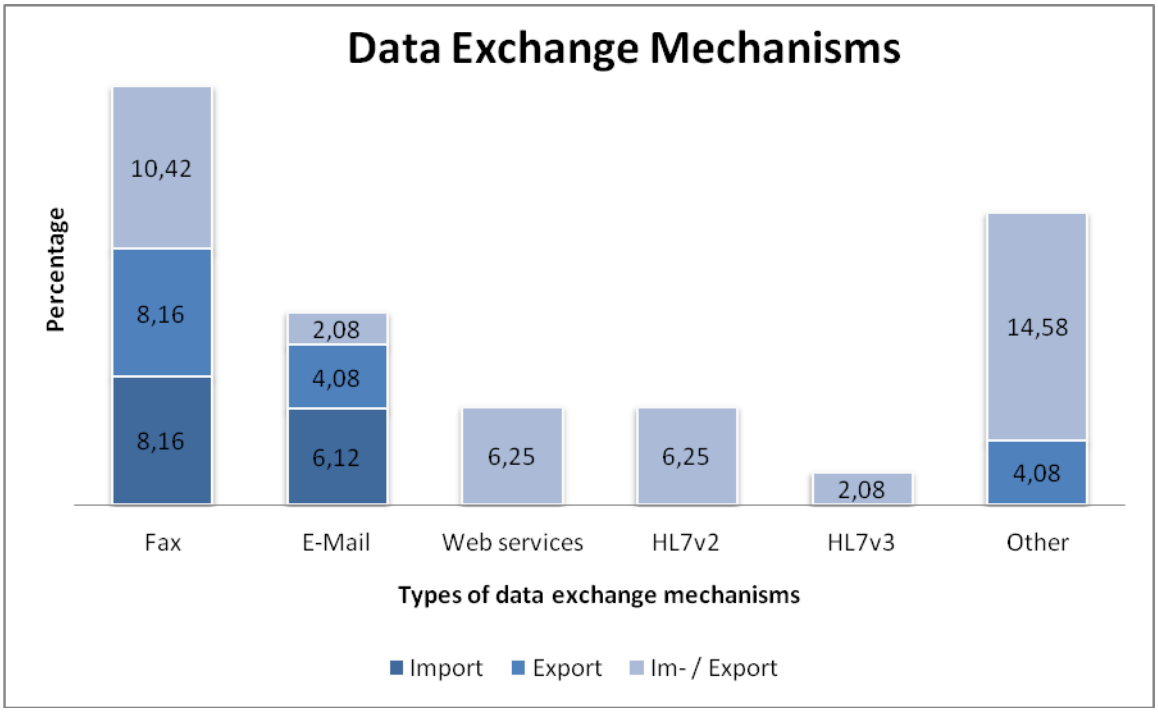

Figure 4: *Percentage support of data exchange mechanisms.*

Interfaces / Data Exchange Mechanisms

In order to achieve acceptance of PHRs by health care professionals, standardized communication protocols and especially data exchange mechanisms are crucial. The most common transport mechanism supported was fax, followed by "other" mechanisms like phone calls, Atom feeds [18], or WebDAV [19] (see Figure 4). Exchange based on E-mail and web services was also supported by some products. The disadvantage of these techniques is that exchanged information may not or only hardly be transformed into structured data due to use of analog or proprietary content formats. Only three systems supported HL7v2 for data, one could handle HL7v3 [20] messages. Regarding standardized data exchange, none of the products claimed fully interoperable support for data exchange through an IHE integration profile. The IHE is an initiative that defines such profiles (for instance XDS [21] or XPHR [22]) for interoperability between systems in the health care domain.

Medical and Non-medical Document Formats

Only few products offered complete or partial support for medical document standards. We found four products supporting the Continuity of Care Record (CCR, see [23]) and two with support for the Clinical Document Architecture (CDA, see [24) and the Digital Imaging and Communication in Medicine (DICOM, see [25]) standard. Surprisingly, we found no product that supported OpenEHR alias EN 13606/EHRcom (for further information see [26] and [27]). Support for non-medical document formats, either text-based or image-based, like the Portable Document Format (PDF) or JPEG images (Joint Photographic Expert Group) was more common (see Figure **5**).

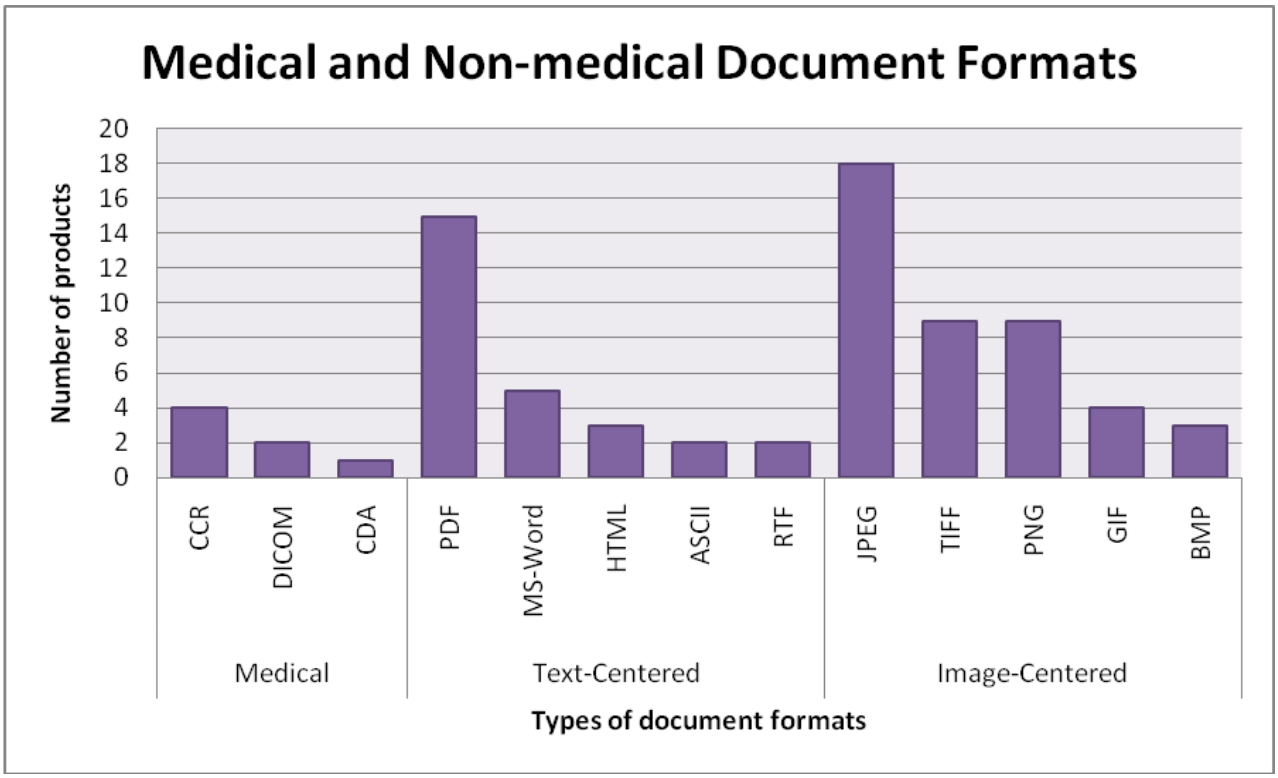

Figure 5: *Absolute number of products supporting different types of document formats.*

Interface

A good interface is essential in order for as many people as possible to benefit from the potential use of PHRs. We focused on seven interesting aspects of interfaces mainly regarding the presentation of information (1-3), technical requirements (4-5), and barriers imposed by culture or national membership (6-7), which we believe are worth mentioning:

- 31 products (equals ≈67 %) offered a printer friendly view.
- 12 products (equals 25 %) offered functions for the visualization of trends, e.g. for the visualization of blood pressure over time.
- 5 products (equals ≈10 %) provided role-specific views for the PHR-content.
- Browser compatibility was tested with Internet Explorer Version 7 and Mozilla Firefox Version 2 because these were the most widespread browsers during the preparation phase of the study (see [28] or [29]). ≈71 % of the PHR supported both browsers without any limitations. The remaining products had little problems mostly with Firefox, but none of them became unusable.
- Browser add-on Requirements: 21 (≈44 %) products required the activation of JavaScript in order to display their user interface properly. One product required ActiveX and one required an installed Adobe Flash player.
- Only 7 products provided localization. Nearly all products' user interfaces and help functions were written in English.
- We found two products being explicitly constrained for use in certain countries.

4 Discussion

Results

The basis for patient empowerment in electronic health records is the amount and quality of structured and computer processable data. As far as we

know, there is no standard or minimal set of structured data that should be used in all PHRs. This would simplify the communication, but would not be useful in all cases, because different PHR implementations have different requirements for their data items. In general, there was good support for different types of structured data in most PHRs. Nevertheless, serious limitations were found regarding input of information. Usage of text fields is error-prone and may lead to unprocessable data. Overall there was a lack of products that support automated data import from mobile devices. This is critical, especially for the home care domain that depends on the patient's ability to document his or her own health state in their everyday life.

The results in the service domain were very heterogeneous. Some products offered many services, but most of them were focused on few special functions. To empower patients, even if they are unconscious, many products offered some kind of emergency function. Perhaps this is because such functions are simple to implement and a strong argument for attracting new users. Another feature, the drug interaction check, was found only in a few products. This may be explained by the challenging prerequisites of structured, coded, and reliable medication data together with a corresponding up to date database for drug interactions. To attract more users, the PHRs should offer more comfort functions that save time and money, e.g. automatic prescription refill or appointment scheduling. For the purpose of patient empowerment the different types of presenting personalized medical content are an important factor to match the individual affection and comprehension of PHR users.

Only a patient who trusts his PHR is able to be empowered by it. Under this assumption insufficient support of privacy, security, or transparency are knock-out criteria for the choice of a PHR. Many products support encrypted data transfer, but give no information on how data is stored and what will be done to prevent data loss and security breaches from inside or outside. At this point most providers should provide more transparency and explain to the user in an understandable way how her or his data is protected and which people have access to it. For us, the best way for the delegation of access rights are fine-grained and meaningful categories. The PHR should also inform the empowered user that she or he is in charge and has the ability and responsibility to grant or revoke access rights for his health-related information from or to other persons (in particular health professionals), so that these can support her or him in a better way. Also, the products should provide a function that explicit transfer the management of the health data to a third party. This is an important function for people who are not in the state to manage this data on their own.

In terms of PHR functionality empowerment means to give the patient the ability and especially the responsibility to manage the own health affairs. This responsibility includes the potential to be misused by the patient, but it raises the question: why should the patient do this, if it maybe leads to a suboptimal treatment? On the other hand, there are psychological reasons that could lead to such a potentially self destructive behaviour. In the end, the situation might be very similar to the existing doctor patient relationship: The physician has to decide whether the information that he receives from the patient is reliable or not. To support this decision making process, the PHR could offer functions like the audit trail (see Table 1 -> Data Protection / IT security category -> Audit trail), which could provide information about the source and editors of a certain data item. Also PHRs are not a replacement for medical records, which have to be the first information source for clinicians.

This study showed the weak penetration of the PHR market with standardized exchange mechanisms for structured medical data like HL7v3 or EHRcom standard. Maybe this is because these standards are complex and cost-intensive to implement. The common way to solve this problem is to manually copy the original document into the PHR. This method is not only uncomfortable and error-prone; it additionally raises the barrier for the usage of PHRs. Regarding this issue providers give away the inter-institutional and space-independent aspect of PHRs and thus a chance for patient empowerment.

The situation in the medical and non-medical documents domain is very similar. Only the less complex CCR standard was implemented in a few products. This contributes to the thesis that most providers avoid the implementation of medical standards in their PHRs due to complexity. However, a standardized medical document format is stable over a long time and assures the time-independent aspect of PHRs. Apart from that, the PHRs offered good support for different kinds of non-medical document formats.

Besides the localization, we could not find serious barriers for the accessibility of PHR content. The precondition of JavaScript as installed browser component is not a real problem, because most modern browsers include such an engine and activate it by default. More PHRs should implement functions for the visualization of health related trends. Such graphs or curves enable the user to monitor her or his own health state and give them feedback information on their efforts.

Limitations

We included a big set of common and domain specific search methods to include the best sources for retrieving relevant PHR products. However, the dynamic structure of the PHR market and the internet as a primary search medium itself makes it hard to guarantee, that our list of PHRs is complete. Also, we can not guarantee that we obtained a significant part of the existing PHRs for our survey.

Regarding retrieval of product details, we had to trust the information that the PHR vendors themselves published on their websites or as answers to our questionnaire. As a counter-check our own investigation with the usage of the demo accounts should prevent major false-positive statements. Nevertheless this does not offer hundred percent reliable results and is one reason why we did not include concrete product names in our survey.

Our survey includes some technical aspects of accessibility, but it was not the focus of this survey to examine all aspects of this domain.

Comparison with Prior Work

According to our best knowledge there has been only little research done in the domain of PHR function evaluation. This confirms to the above mentioned statement of Kaelber et. al. in [10].

Dumitru et. al. [30] compared four PHRs that were stable on the German market over time. Kim [31] evaluated twelve products regarding their capability to provide enough information for the purpose of medical usage by users and providers. Another publication examined the functional status of several PHRs [32].

Further publications evaluated only single health records products (e.g. [33] and [34]) or other aspects of the PHR theme e.g. security mechanisms [35], implementation and design questions [36], [37] and [38]), or properties of an ideal PHR [39].

The above mentioned CITL-Report (see [9]) was sponsored by different global players. Many of them are also vendors which have their own PHR products. The report lists the benefits of PHRs, examined their costs and net value but does not focus on patient empowerment nor investigates the functions of real products.

Future Work

We intend our research to provide a basis for further work on the field of patient empowerment and PHR research. However, many open questions still remain. Some of these are:

- Which entry type method is appropriate for the different categories of information?
- Which type of information representation is appropriate?
- How can high quality structured (and maybe coded) information be entered by the PHR user?
- Which type of help functions should be offered by the PHR?
- Which services should be offered to which types of users?
- Which technical standards have to be supported for security and interoperability?

These questions show that many design specific aspects of a PHR are highly depending on the characteristics of the user. Further studies with different user profiles differing in their social status, computer skills, age, and diseases should be conducted. Such a scenario-based approach enables the generation of more qualitative information on the question which type of PHR functions are the best for empowerment of different types of users.

5 Conclusion

For the Identification of functions and properties that allow the patient to play an active role in her or his own health management, we performed a literature study and finally created a function taxonomy including six function domains. In a second step we collected PHR systems from different sources and created a revised list with 48 products which are currently available on the market. Finally, we analyzed the functions of each PHR with information we got from an explorative use of demo-accounts, from the vendor websites, and through the analysis of questionnaires.

In general, we found that the examined PHRs provide a comprehensive set of means for entering structured data but also that there are big differences between the qualities of the entry methods. Only a few products show technical barriers that prevent users from daily use of their systems. We found many interesting services especially within the information acquisition and representation domain. Nearly all providers fulfill the "must have" requirement of a secured access of the user to a PHR. The next steps in empowering patients are help functions with explanatory texts that support users in entering data and in how this information can be obtained. The quality of data will increase if the PHRs support safe entry methods that reduce failures whenever possible. Good examples are the questionnaires for generation of advanced directives or a testament. Some PHRs could generate a legally correct text that the user could print and sign. If something changes in the legislation, the PHR can update the text and inform the user that his document is outdated. However, the commitment for security mechanisms of many providers was ending at this point. As a next step they should make clear statements about the encryption of the stored data and the key ownership to offer more transparency to their users. We found only a few products that claimed support for standard medical document formats or protocols. The implementation of these standards is highly important because they are stable in time and enable the exchange of data with other actors of the health care domain and further processing. This provides a solid basis for the next generation of distributed health services and the simplification of today's manually and error-prone user entries. We believe that the usage of these standards is also a prerequisite for the willingness of the user to manage health data in a PHR and for health professionals to use this data and therefore this is an important requirement for PHRs.

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Appendencies

Search Terms

- ("2008"[Publication Date] : "2008/10/01"[Publication Date]) AND ("phrs")
- ("2008/01/01"[Publication Date] : "2008/10/01"[Publication Date]) Andes]) AND ("personal health record")

Questionnaire

- Which kinds of medical document formats does your product use / interpret? (e.g. CDA, DICOM)
- Which kinds of non-medical document formats does your product use / interpret? (e.g. DOC, JPEG, MPEG2)
- Which interfaces can be used to exchange data between your system and other health providers' IT systems? (e.g. HL7v2, Web Services)
- Is the exchange of data with other medical organizations encrypted? If so, what kind of encryption do you use? (e.g. SSL 2.0)
- Do you use encrypted data-storage on the server-side? If so, where is the key stored?
- Is it possible to grant different kind of access rights, like read only, read-write, delete and update?
- In which granularity do you grant access rights? (e.g. for the whole record, for individual documents or specific categories)
- Are there external products that interoperate with your system? (e.g. blood pressure meter from…, clinical information system from…)

Domain	Categories	Description	Example
Structured Data	Patient demographics	Demographic information	Name, Date of birth
	Medical base data	Most important medical information	Blood group,
	Additional medical data	Other medical data that can be useful	Weight, height
	Health insurance	Administrative data about the patients health insurance	Insurance ID and address of the company
	Medication	List of prescriptions that are consumed	Name of the prescription and further intake instructions
	Allergies	List of known allergies	„Hay fever“ or „Penicillin incompatibility“
	Vaccinations / Immunizations	List of known vaccinations and immunizations	“Polio”
	Diagnoses	List of known diagnosis	“Conjunctivitis”
	Treatment / Procedures	Medical procedures applied to the patient	“Appendectomy”
	Conditions / Symptoms	List of observed conditions and symptoms	“dizziness in the morning”
	Test / Laboratory results	Results of physical examinations	“Lactate=2,0 mmol/l”
	Family history	Known diseases and problems of family members	“Mother had depressions”
	Data from mobile devices	Measurements data	“Average pulse rate = 87”
	Sports / Fitness data	Data about exercises	“Badminton 1 times a week”, “2009-05-21: Absolved a 5 kilometers run”
	Organ donor	Remove of organs after patients death	“I agree that my organs could be removed after the medical finding of my clinical death”
	Declaration of patients will	Advanced directives of the patient	“Turn of breathing machine in case of more than twelve months in coma”
	Medical addresses	Addresses from persons who have an health related connection to the patient	“Dr. Henry Levin, Urologist, Fakestreet 1”
Services	Management functions for multiple users	Functions to manage health data of other persons	A mother can create a new account for her daughter
	Prescription management (history / order)	Prescriptions taken in the past. Functions to order new prescriptions	List of historical prescriptions, patient receives an reminder if the package becomes empty
	Emergency access	Ways to access the data, even if the patient is	Unlock most important information

		unconscious	through account data, that is printed on a card in the patients pocket
	Drug interactions	Check, if a combination of drugs can cause interactions	Penicillin together with cough-syrup cause liver damage
	Medical information	All kinds of information retrieval and presentation for the patient	Medical Encyclopedia, Diabetes tips
	Professional / Community information	Information that have health care professionals or a community of persons as source	Secure Communication with physicians, experience exchange with persons who have the same disease
	Calendar / Journal / Appointments / Reminders	Management and comfort functions for the administration and documentation of health	E-Mail reminder for appointments, Health state diary
	File upload for unsupported document types	Could types of documents be uploaded, which will not be interpreted by the system	A scanned referral letter
Data Protection / IT-security	Encrypted communication	Encrypted communication between the PHR-user and the PHR system	https with AES256, SFTP
	Encrypted data storage	Is the data encrypted when stored?	RC2, key is managed by the patient
	Access rights	Which types of access rights could be granted?	Read, write, update, delete
	Identification through digital signature	Authentication of a person	RSA
	Time-based access	Are access-permissions restrictable in time?	Granting complete access for Doc. Brown for the next seven days
	Role-based access	Are there predefined types of access right for special roles?	All Radiologists can read surgeries
	Level of granularity	In which granularity can access rights be permitted?	Information-level: Name, predefined categories: Patient Demographics, whole profile
	Audit trail	Log of denied or granted access to information inside the PHR	Doc. Brown read Surgeries on 2009-05-21
	Usage of certificates	Digital certificates which proof the systems identity	Certificate in the X.509 standard
	Others	Other types of access control mechanisms	Personal Identification number, key on an USB-stick
Interfaces / Data Exchange Mechanisms	XDS	IHEs Cross Enterprise Document Sharing, XDR or XDM profile	XDR together with the XPHR content profile allows the integration of data from electronic medical records.
	HL7v2	A widely spread standard for medical	For the integration of laboratory results

		communication	
	HL7v3	Successor of the HL7v2 standard	For the integration of referral letters
	Web services	An electronic service that support the interaction between applications	A service that provides an programming interface to calculate the risk of an heart attack with the data from the PHR
	FTP / SFTP	File Transport Protocol	Upload of a bunch of scanned documents to the PHR
	HTTPS / HTTPS	Hypertext Transfer Protocol	Enter a date in a field inside a website
	E-mail	Electronic mail	Sending a question to a physician
	Fax	The Telefax Protocol	Sending of an document
	Other	All other types of interfaces for data exchange	ATOM feeds, phone
Medical and Non-medical Document Formats	CDA	The HL7 Clinical Document Architecture	Storing of an physician referral as CDA-Document
	CCR	The Continuity of Care Record	Create an extraction of the most important medical data from the PHR as source of these data
	DICOM	The Digital Imaging and Communications in Medicine Standard	Display of an X-ray image from the clinic inside the PHR
	EHRcom / OpenEHR	The Electronic Health Record Communication (EN 13606) Standard	Updating blood pressure inside the PHR through uploading a OpenEHR Document
	Text centered	All text centered formats	Display of an Open Office Document
	Image centered	All image centered formats	Display of an PNG picture
	Audio / Video centered	All audio- or video centered formats	Play an MP3 with heart tones of a child, Display of an MPEG4 Ultrasonic movie
Interface	Role based	A view that differs depending on the role of the user	A physician sees the correct medical terms while a patient sees simpler terms
	Printer friendly	A view that is optimized for printer output	An x-ray image is scaled to one DIN A4 Page of paper
	Visualization of trends	Visualization of measurements	Display a set of blood pressure measures as a curve
	Browser requirements	Technical prerequisites for browser plug-ins or settings	Activated Cookies, Installed Flash Player
	Browser compatibility (Firefox 3, Internet Explorer 7)	Is the website still navigatable in these Web-browsers?	Using Firefox to enter structured information in a PHR

	Localization	Localization of the contents	Translation of texts, usage of local currency or separators
	Explicit limitation to national healthcare systems	Some systems are restricted to single nations.	System X is restricted to the USA

Table 1: *Function Taxonomy Checklist*

Name	URI
AccessMyRecords	http://www.accessmyrecords.com/
Akte Online	https://akteonline.uni-muenster.de/ao_v29/login.php?
Avetana	http://www.avetana-gmbh.de/avetana-gmbh/referenzen/akte.xml
CrisisID	http://www.crisisid.com/
dLife	http://www.dlife.com/
Dr I-Net	https://www.drinet.com/mymedical.asp
Elder Issues	http://www.elderissues.com/
followMe	http://www.followme.com/index.html
GlobalPatientRecord	www.globalpatientrecord.com
Google Health	https://www.google.com/accounts/ServiceLogin?service=health
Health Records Online	http://www.healthrecordsonline.com/
HealtheTracks	https://secure.healthetracks.com/welcome.cfm
Healthgram.com	https://www.healthgram.com/
HealthTracer	http://www.healthtracer.com/
iHealthRecord	http://www.ihealthrecord.org/
Laxor	http://www.laxor.com/
LifeNet	http://www.lifenetcard.com/
LifeSensor	https://www.lifesensor.com/de/de/de-hn/gesundheitsbewusste.html
Lynxcare	http://www.lynxcare.net/
Magnuns Health Portal	http://magnushealth.com/
MedDataNet	http://www.meddatanet.com
Medefile	http://www.medefile.com/
MedFile.com	https://www.medsfile.com/AccountHome.aspx
MedicAlert	https://www.medicalert.org/
MedicalIDCard	http://www.med-id-card.com/
MedicalSummary	https://www.medicalsummary.com/
MediKeeper	http://www.medikeeper.com/
MedNotice	http://www.mednotice.com
Microsoft Health Vault	http://www.healthvault.com/
Mivia	https://www.mivia.org/Default.aspx
My Doclopedia PHR	https://www.doclopedia.com/MyDoclopedia/
myHealthFolders	https://myhealthfolders.com/
MyLifeSaver	https://www2.doctorglobal.com/
MyMedicalRecords	https://www.mynetrecord.com
MyMediList	http://www.mymedilist.org/
NoMoreClipboard	https://nomoreclipboard.com
Patient Power	http://gtipatientpower.com
PersonalMD	http://www.personalmd.com/
RevolutionHealth	https://www.revolutionhealth.com/
Securemed	https://www.securamed.com
Telemedical RelayHealth	https://app.relayhealth.com/Welcome.aspx
TheSmartPHR	http://www.smartphr.com/10/
TouchNetworks	http://www.touchnetworks.com/default.php
VitalChart	http://www.vitalchart.com/
vitalEsafe	http://www.vitalesafe.com/
WebMD Health Manager	http://www.webmd.com/health-manager
WorldMedcard	http://www.worldmedcard.com/wmclite/index2.jsp
ZebraHealth	https://www.zebrahealth.com/ReadMore.aspx

Table 2: *List of examined PHRs.*