An analysis of free Web-based PHRs functionalities and I18n

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Abstract— The growth of the Internet, Web technologies, and other electronic tools are allowing the public to become more informed and actively engaged in their health care than was possible in the past. Personal Health Records (PHR) offer users possibility of managing their own health data. Many patients are using PHRs to communicate with doctors in order to improve healthcare quality and efficiency. A large number of companies have emerged to provide consumers with the opportunity to use online PHRs within a healthcare platform, proposing different functionalities and services. This paper analyzes and assesses the functionalities and internationalization (i18n) of free Web based PHRs.

I. INTRODUCTION

Personal health records (PHRs) are currently becoming increasingly more popular for patients and consumers, the estimated number of people in the US with access to PHR systems is being 70 million [1]. A PHR is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and to make appropriate parts available to those who need it. PHRs offer an integrated and comprehensive view of health information, including information that people generate themselves [2]. This kind of application allows health activities to be tracked and supported throughout a patient's entire life experience, and is not limited to a single organization or a single health care provider [2].

The PHR should provide different functionalities which are easy to use and understand, which are customizable to fit personal needs in information retrieval and help individuals to organize personal health information. Furthermore, PHRs can help individuals with general health education, and educate them as regards their personal health information. However, not all the Web providers provide their users with the same functionalities and applications.

An analysis of the features and functionality of USB-based Personal Health Records was carried out in [3] to determine the features of commercially available USB based PHR devices, and compare the commercial state of the art with recommendations made by certification committees. With the best of our knowledge, no paper has analyzed the functionalities of Web based PHRs. The aim of our paper is

to analyze and to assess the functionalities of 19 free Web based PHRs. The search of PHRs performed in this research has been addressed through the use of a Systematic Literature Review (SLR).

This paper is structured as follows. Section II describes the research method that was used in this paper. Section III shows the main results of the data collected. The main findings are discussed in Section IV. Finally, Section V presents our conclusions and further work.

II. METHOD

A. Systematic Review and Protocol

The objective of this work has been achieved through a SLR which used formal methods to ensure that search and retrieval process were accurate and impartial. In this paper, we followed the quality reporting guidelines set out by the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) group [4]. Before beginning the search for literature and the data extraction, a review protocol was developed in which each step of the systematic review was described, including eligibility criteria.

B. Eligibility Criteria

The following inclusion criteria were used: (IC1) PHRs with Web-based format; (IC2) PHRs which were free.

C. Information Sources

The following sources have been selected to perform the SLR: Medline, ACM Digital Library, IEEE Digital Library and ScienceDirect. The *myPHR* Website was also an information source for our research. This Website contains information related to the use and the creation of PHRs, and was created by the American Health Information Management Association (AHIMA) to help individuals become better managers of their own personal health information.

D. PHR Selection

The PHR selection was organized according to the following five phases:

1) The usage of the following search string: ("PHR providers" or "PHR website") to search for publications in electronic databases related to health and computer science.
2) The articles selected were explored in order to discover the names of Web-based PHRs.
3) The search for PHRs on the *myPHR* Website.
4) The selection of the PHRs found based on eligibility criteria IC1 and IC2.

5) The exploration of each PHR Website in order to identify and analyze its functionalities.

The above activities were carried out independently by C.L. Seva Llor, J. L. Fernández and I. Carrión. Any discrepancies were resolved by the rest of the team, A. Toval and S. Ouhbi.

E. Data Collection Process

Data collection was carried out by using a data extraction form. Each PHR was assessed by two authors of this paper in order to explore its functionalities. The Cohen's Kappa coefficient was used to calculate the interrater agreement between the two researchers in their evaluation. The Kappa coefficient was 0.97, which, according to Landis and Koch [5], indicates an almost perfect agreement between the two assessments.

F. Data Items

We designed a template with the data that should be extracted from each PHR. The fields were chosen based on the features provided by a typical PHR [6]. The data collected were tabulated to show:

- *General*: Link of the PHR.
- *Health information.* Laboratory tests, medical images, allergies, glucose level, blood pressure, blood group, weight, height, immunizations, medication, family history, social history (e.g smoking status, alcohol history) and emergency contact.
- *User action.* Add, modify or remove information, grant access, information sharing, import information and export information.
- *Connection with.* Healthcare providers (i.e. EHR systems), other PHRs, health devices, third-party applications, social networks and laboratories.
- *International access.* Multi-language PHR.

G. Quality Assessment

We evaluated each PHR using quality assessment questions for each data item:

Health information (H):

H1 Does the PHR provide the user with his/her illnesses history?

H2 Does the PHR provide the user with his/her personal information?

H3 Does the PHR provide the user with his/her medication list?

H4 Does the PHR provide the user with his/her family history?

H5 Does the PHR provide the user with his/her social history?

H6 Does the PHR provide the user with emergency contact info?

User action (U):

U1 Can the patient add information to his/her profile?

U2 Can the patient modify his/her profile?

U3 Can the patient remove information from the PHR?

U4 Can the patient grant access to his/her profile?

U5 Can the physician add information to the PHR?

U6 Can the physician modify information in the PHR?

U7 Can the physician remove information from the PHR?

U8 Can the physician grant access to his/her profile?

U9 Can the PHR user share information?

U10 Can the user import information to the PHR?

U11 Can the user export information from the PHR?

Connection with (C):

C1 Can the PHR connect with healthcare providers (EHR systems)?

C2 Can the PHR connect with health devices?

C3 Can the PHR connect with other PHRs?

C4 Can the PHR connect with third-party applications?

C5 Is the PHR connected with social networks?

C6 Can the PHR connect with laboratories?

International access (I):

I1 Does the PHR provide more than one language?

The questions were scored as follows:

- Yes (Y), if the PHR can offer this functionality. Y = "1 point".
- No (N), if the PHR does not provide the user with this functionality. N = "0 point".

III. RESULTS

A. PHR Selection

A total of 19 PHRs were selected from 47 PHRs found in our search. Some PHRs were discarded since they did not meet the criteria IC1 and IC2. Figure 1 shows the process of the PHR selection.
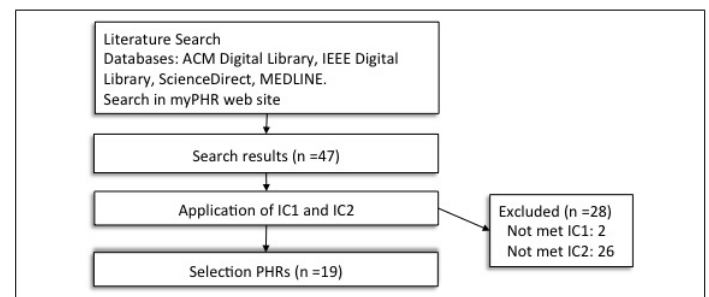

Fig. 1. PRISMA Flow Diagram

B. Quality Evaluation of PHRs

Table I shows the quality assessment result for each PHR. Figure 2 presents the classification of the PHRs selected. This classification is based on the calculation of the score of each PHR. The average quality scores for PHRs is 12.89 (out of 24) which indicates a medium level of functionality. *Microsoft HealthVault* provides the user with a large number of functionalities. Although, this PHR does not offer the user his/her social history (e.g smoking status, alcohol history), third-party applications such as CardioSmart can provide this kind of functionality. In contrast, EMRySTICK achieved the lowest score (6 out 24).

TABLE I

QUALITY EVALUATION OF PHRs

| PHR	H1	H2	H3	H4	H5	H6	U1	U2	U3	U4	U5	U6	U7	U8	U9	U10	U11	C1	C2	C3	C4	C5	C6	I1	T	%
DrI-Net [7]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y	N	Y	Y	N	N	N	N	N	N	14	58
HealthyCircles [8]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	N	N	N	Y	N	N	N	18	75
Microsoft HealthVault [9]	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	23	96
NoMoreClipBoard [10]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y	N	Y	Y	N	N	N	19	79
RememberItNow! [11]	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	N	N	N	N	N	N	N	N	16	67
EMRySTICK [12]	Y	Y	Y	N	N	N	Y	Y	Y	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	6	25
myMediConnect [13]	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	N	N	N	N	N	N	N	16	67
HealthButler [14]	Y	Y	N	Y	Y	N	Y	Y	Y	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	8	33
Juniper Health [15]	Y	Y	Y	Y	Y	N	Y	Y	Y	N	N	N	N	Y	N	N	N	N	N	N	N	Y	N	N	10	42
MedsFile.com [16]	Y	Y	Y	Y	N	Y	Y	Y	Y	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	8	33
My Doclopedia PHR [17]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N	N	N	N	N	13	54
myHealthFolders [18]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N	N	N	N	N	14	58
My HealtheVet [19]	Y	Y	Y	Y	N	Y	Y	Y	Y	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	N	9	38
Telemedical.com [20]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	N	N	N	Y	20	83
PatientsLikeMe [21]	Y	Y	N	N	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N	N	N	N	N	13	54
ZebraHealth [22]	Y	Y	Y	Y	N	Y	Y	Y	Y	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	8	33
dLife [23]	Y	Y	Y	Y	N	N	Y	Y	Y	N	N	N	N	Y	N	N	N	N	N	N	N	Y	N	N	8	33
PatientPower [24]	Y	Y	Y	Y	N	Y	Y	Y	Y	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	8	33
WebMD Health Manager [25]	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N	N	N	N	14	58
Total	19	19	17	15	9	13	19	19	19	11	10	10	10	10	9	4	9	5	1	4	3	6	1	3	-	-
%	100	100	89	79	47	68	100	100	100	58	53	53	53	53	47	21	47	26	5	21	16	32	5	16	-	-
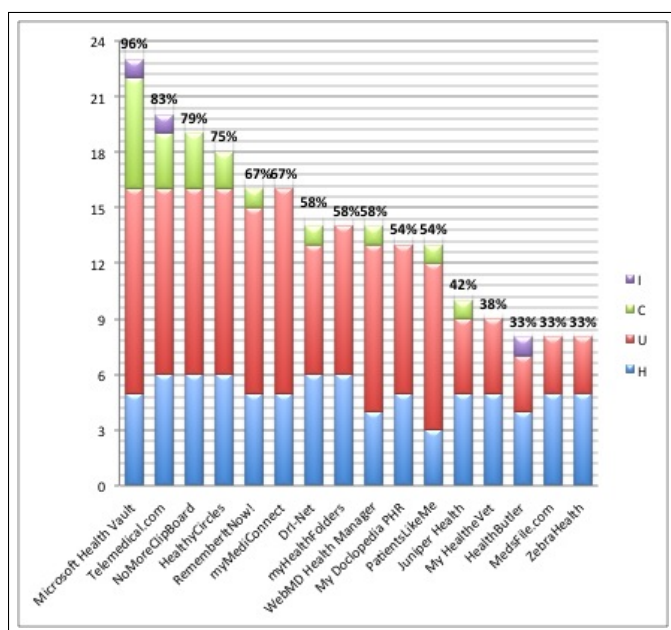
Fig. 2.   PHRs classification

IV.   DISCUSSION

A. The functionalities of the selected PHRs

In an attempt to study the functionalities of the PHRs, each PHR was analyzed using quality assessment questions. These questions were broken down into 4 items:

1) Health information: Table I shows that all the PHRs selected provide illness history and personal information. However 21% of the PHRs do not offer the user his/her family health history. Family health history is an important risk factor for both common chronic diseases and genetic disorders. Recognizing patterns of familial disease can help to identify preventive interventions, including genetic testing technologies [26]. Hospitals do not normally have a history of sharing information which encompasses all family members, so this functionality is a significant contribution to the patient's continuity of care. Nevertheless, a good

agreement among family members must be assumed in order not to contradict the confidentiality of personal health information/data [27]. In contrast, only 47% of the PHRs allow users to include and track their social histories.

On the other hand, 68% of the PHRs selected provide the user with emergency contact. This data contrasts with a previous study in which 12 out of 13 USB-based PHRs analyzed included an emergency entry. Emergency contact is an important feature which permits the appropriate healthcare professionals (previously authorized by the user) to access users' data. Some PHRs, such as Microsoft HealthVault, allow users to select what information will be shared and with whom in the case of an emergency. Nevertheless, emergency access increases the risk of data breaches. Some national laws assume implicit patient consent in an emergency situation [28], which does not guarantee the privacy of patients' data.

2) User action: 100% of the PHRs selected give patients the right to modify, change and remove information, and 58% grant the patient access to the profile, while only 53% of the PHRs selected provide these functionalities to physicians. We believe that this aspect should be improved, although some physicians have expressed their concerns because the information stored in PHRs might be less accurate if patients do not know what exactly is included [29]. Moreover, when the information comes from several sources, greater privacy and security risks exist.

47% of the PHRs selected provide the user with the possibility of sharing the information. 47% of the PHRs allow the user to export data, but only 21% allow the user to import data. Different formats can be found: proprietary binary format, proprietary XML format, PDF, txt, CCD and CCR format.

3) Connection with: 26% and 21% of the PHRs selected are connected with EHR systems and other PHRs, respectively, while only 5% can connect with other health devices and laboratories. We can observe in Table I that 16% can be linked to third-party applications. Mobile phones are a particularly attractive avenue for delivering health interventions because of their widespread adoption. ubiq-

uity, and increasingly powerful technical capabilities. Five intervention strategies have been used in phone-based health interventions [30]: (1) tracking health information, (2) involving the healthcare team, (3) leveraging social influence, (4) increasing the accessibility of health information, and (5) utilizing entertainment. Table II presents the PHRs that are connected with other PHRs, third-party applications and social networks. Note that 32% of PHRs selected are connected with a social network. However, the use of social networking implies privacy and security issues, particularly as regards the sharing of information related to family members.

TABLE II
PHRs CONNECTION

PHR	Connected with
Other PHRs	
HealthyCircles	Microsoft HealthVault
NoMoreClipBoard	My Medicare, Microsoft HealthVault
myMediConnect	Microsoft HealthVault
Telemedical.com	Microsoft HealthVault
Third-party application	
HealthyCircles	Neighborhood Nurse, AMA Adult Tool, Midwest Heart Specialists
Microsoft HealthVault	More than 100 applications
NoMoreClipBoard	Pain Management with ReliefInsite
myMediConnect	Wellness Tracker (Nutrihand), eRadiology Room
Telemedical.com	Hill Physicians
Social networks	
HealthyCircles	LinkedIn, Facebook, Twitter, Google+
Microsoft HealthVault	Facebook, Windows Live, Twitter
RememberItNow!	Facebook, Twitter, LinkedIn, Youtube
Juniper Health	Facebook, Twitter
dLife	Facebook, Twitter and YouTube
PatientsLikeMe	Twitter, Facebook, Wikipedia, YouTube, Flickr

4) International access: All the PHRs selected are in English. Only 3 PHRs (*Microsoft HealthVault, HealthButler and Telemedical.com*) provide the user with a second language (Spanish). Other internationalization issues such as the units of measure are important aspects in laboratory results, route and dose in medications [31].

B. Limitations

This study may have several limitations: the search was a manual search process of several databases; the search string may not have included words that would have selected other relevant PHRs; and the raters of the PHRs selected may have omitted data that might have been relevant to this study.

V. CONCLUSIONS

This paper has analyzed and assessed the functionalities of 19 free Web based PHRs. A questionnaire containing 24 questions was defined to assist PHR stakeholders to select the PHR that best fits their needs. PHR designers have also been given the opportunity to benchmark from other PHRs. Our findings show that not all PHRs provide the same functionalities (e.g. PHRs that are designed for nursing, family or the military). We trust that our research may help practitioners to discover the functionalities that exist in current free Web-based PHRs. In future work, we intend to analyze the usability issues [32] and internationalization requirements [33] of the PHRs.

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