Lessons Learned After Redesigning a Personal Health Record

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Abstract

On May 2016, our institution implemented a redesign of the personal health record (PHR) with the aim of enhancing its use. The objective of this research was to know and to understand end users' opinions as regards PHR functionalities and the difficulties they have addressed while using the new PHR version. Research was based on a self administered survey, patient interviews and focus groups performed with out-patients. Topics examined: ways of access to the PHR log-in web page, frequency of use, type of device, most used functionalities, the different uses patients gave to PHR, perception as regards the redesign. This research allowed us to know the uses patients give to the PHR in this institution and to understand the difficulties they found in what refers to its re-design. This information constitutes the clue to motivate and accompany PHR users in the process of adoption of a patient portal.

Keywords: Personal Health Records; Person-Centered Design, Consumer Health Information.

Introduction

The Personal Health Record (PHR) has been defined as a set of computer-based tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it [1]. They usually consist of provider-tethered applications that allow patients to electronically access health information documented and managed by a healthcare institution. Although patient portals are already being implemented, it is still unclear in which ways these technologies can influence patient care [2]. Within the aims of PHRs are communication, empowerment, portability, education, participation and self management [1;3].

To ensure the use of PHRs as a patient engaging and empowering tool regarding healthcare, patient adoption of the tool is crucial. Nevertheless, PHRs have not yet reached the levels of use expected. This fact can contribute to the delay of PHRs in reaching their potential [4]. It is reported in the literature that several issues could be obstructing PHR adoption by patients. Barriers to technology or internet access, and patients' health literacy levels are some examples [5]. Less attention has been paid to the quality of the patient–provider relationship related to portal use; this may be an important barrier to or facilitator of use [6]. Some patients had expressed their concern over whether this new technology might replace conversations between patients and physicians [7;8].

There are several studies reporting less PHR adoption among ethnic minorities and young healthy adult patients [9]. By contrast, a higher adoption is evidenced in disabled, chronically-ill individuals and their caregivers [10;11]. At present, no clear consense exists as the reasons of this low PHR adoption.

In May 2016, our institution implemented a redesign of the PHR with the aim of enhancing its use through different changes. Even when the hospital PHR was considered by patients as valuable and useful, their functionalities, accessibility and usability were limited. The needs of the different actors along with technological improvements and possibilities started to grow and thus, the project required a redesign process.

We applied user centre design techniques in each module, so as to improve interfaces, as one of the priorities. Other goals were to rearrange the administrative and clinical functionalities separately, and to adapt PHR to all types of devices. The redesign process was mainly focused on the flow rearrangement of each of the tasks in the working space. For this project to take place, a multidisciplinary working team was constituted. Its members were medical informatics and attending physicians, nurses, software developers and usability analysts. They agreed to work with user centre design and agile development methodology scrum approaches. By this mean, hospital patients not only would be a source of information, but also main characters of this redesign, during an iterative and incremental process in favor of continuous improvement.

The implementation was performed in a gradual manner, starting at January 2016. At first, patients could, optionally, log in to the new version and test it. Those who chose to try it also had the option to go back to the previous version. According to the registered data, between January and April 2016, few PHR users had chosen using the new version (only 10 %, from 240 000 users). Once the design, development and testing of the new version was complete, on May 2, 2016, the new PHR version was fully implemented. The choice to use the previous version of PHR was not available any more for any patient. This change result in a significant increase in the users' help-desk and support requests. From the analysis of the support needs, it came out that the difficulties in the use of the tool were mainly due to the interface changes. Taking this issue into account, we considered the necessity of carrying out inquiries with users/patients. In this context, new interviews, a survey and focus groups were performed.

The aim of this research was to know and to understand end user' opinions as regards PHR functionalities and the difficulties they have addressed while using the new PHR version. Besides, we analyzed the project lessons learned.

Methods

Settings

The Hospital Italiano de Buenos Aires (HIBA) is a non-profit healthcare academic center founded in 1853. The HIBA has a network of two hospitals with 750 beds (200 for intensive care), 41 operating rooms, 800 home care beds, 25 outpatient clinics and 150 associated private practices located in Buenos Aires city and its suburban area. Between 2013 and 2014, over 45,000 inpatients were admitted to its hospitals, and there were 45,000 surgical procedures (50% ambulatory) and 3,000,000 outpatient visits. Since 1998, the HIBA has run an in-house-developed health information system, which includes clinical and administrative data. It has been recently certified by the HIMSS as level 6+ in the Electronic Medical Record Adoption Model, being the first hospital in Argentina and the second in Latin America reaching this stage. The HIBA health information Department, is in charge of the design, development, implementation and maintenance of almost all systems, including the EHR and the PHR, as well as the administrative systems [12;13].

Research carried out in 2014, described the mean age of the PHR users as 55,5 years old, being a 60,5 % female. The rate of registered users was almost 50 % while the rate of use was of 29,1 % [14].

Interviews and focus groups

This qualitative research was based on patient interviews and focus groups. Personal interviews were performed with out-patients in waiting-halls. A semi-structured guide was used for the sessions. Questions for the interview were prepared by our multidisciplinary portal implementation team (physicians, psychologists and nurses). Questions included: the different uses patients gave to PHR, frequency of use, perception as regards the redesign, etc. The recruitment for the interviews was performed in the waiting halls, with the collaboration of the different hospital administrative areas, which facilitated selection of those patients that were waiting to be attended. Each session was integrated by a facilitator and an observer.

In order to recruit participants for the focus groups, an announcement in the hospital web page and in the PHR was published. Applicants were asked to complete a form confirming attendance.

A semi-structured methodology with discussion triggered motivations was applied [15;16] Sessions were conformed by a facilitator (researcher and co-researcher) who conducted the conversation such that all participants could express their opinions concerning the proposed objectives. An observer was in charge of registering the encounters. The introduction was standardized by the researcher/co-researcher of the sessions; the aim of the encounters was explained, without naming any adjective. The focus group researcher/facilitator did not interfere with her particular cultural beliefs or preconceptions with respect to the research subject. Both the focus groups and the interviews were recorded and transcripted for further analysis. Also, an observer obtained written records at that moment in order to register non-verbal information.

This study obtained the approval of the Ethical Committee for research projects of our hospital. Once the aim of the study and the confidentiality of the given information were ensured, all participants gave their written informed consent before being included in the study. The study was conducted according to the World Medical Association Declarations of Helsinski dispositions and the clinical guidelines for best practices ICH E6.

Collection and further analysis of obtained data was carried out by two professionals. It was made by the codification and categorization of data based on a process of constant comparison according to Grounded theory [18]. Researchers reviewed the data collected, and repeated ideas, concepts or elements that became apparent were tagged with codes, which have been extracted from the data. Codes were grouped into concepts and then into categories. These categories serve as an orientation for the presentation of results in this article.

Survey

A self administered survey was conducted with a group of patients, who were selected because of the frequency of PHR use and because they had made suggestions through our support system. The survey was made by usability and qualitative testing experts, based on the need to characterize the way patients use the PHR application. Several topics were examined: ways of access to the PHR log-in web page, frequency of use, type of device, and most used functionalities. Furthermore, surveys considered use of the news section, where patients could find health information. Finally, there was a free text space left for comments. The results of the survey are expressed as a percentage.

Results

Interviews and focus groups

From June to August 2016, fifty one interviews were conducted in waiting halls of traumatology, ophthalmology, gynecology and obstetrics, internal medicine and surgery departments. Participants were from 30 to 80 years old, with an average of 65 years old.

Six focus groups with the participation of twenty six patients were also performed. The participants were from 30 to 95 years old, with an average of 68 years old.

From the analysis of the interviews and focus groups, analytical dimensions arose as follows.

The first one was related to the use patients gave to the PHR. We list the following answers in order of frequency: setting up medical appointments and its scheduling reminder functionality, asking for consultations to specialty physicians and for prescription renewals, visualization of medical bills and medication list visualization. Patients also read PHR news, social announcements, and they use the messaging system to communicate with their primary care physicians.

The second dimension was related to the different problems that came up after the redesign. We could differentiate:

- Technical issues
- Problems specifically related with the new design
- Change resistance
- A spectrum of needs that went from their need to be listened, to the preference to know those individuals who resolve their demands and complaints.

Several comments made by patients during the interviews and focus groups were textually quoted.

Technical issues

Participants named difficulties signing in at the PHR, mistakes on the PHR web page, password issues, problems with the web browser, and difficulties to understand the new interface.

- "At first, some red flags with the label: -*The user does not have access*- appeared. This means you publicited the new PHR without having the system running properly yet."

- "I cannot enter to the PHR using the explorer browser."

Problems related specifically to the new design

One of main reasons of discomfort with the PHR redesign was patients' belief that several of the most used functionalities were not available any more. In fact, however, patients were merely not able to find them with the new organization.

- "I cannot find the consultations anymore."
- "Since the format had been changed, I couldn´t send messages to my primary physician. It is hard for me to get familiar with this new format."
- "I could not find the way to purchase medication."
- "Before the change, I could visualize my x-rays or ultrasounds, but now, not anymore."
- "I click, and a sign appears, *-The bill have been downloaded*- Where it appears downloaded? I do not know where it is."

Concerning the typography size, patients found it too small. In some cases, they had difficulties understanding the icon meanings.

- "Anterior versions were of easier access. The same with the icon sizes. For example the messaging icon is smaller now."

Another aspect that appeared was the need to enhance the visibility of certain functionalities, by placing them at the main menu with direct access. By this we mean facilitating patient access to them in a simple and agile manner.

Change resistance

taking into account that every change brings along different effects, PHR users were affected. This inquiry enabled us to understand that even if users might have regular access to information and communication technologies, a digital gap exists. It is acting as a barrier for the adoption of this tool, considering the high average age of our hospital population.

- "I do not understand computers."
- "I want to avoid having to think. I rather prefer the PHR tell me what to do than me having to ask for the information."
- "Simplify it. Do not try to improve those things that do not need to be improved."
- "When the PHR was changed, I got angry because I have to adapt mysel.f"
- "We have to accept that is a chronological issue. I am sure that if I ask my grandson, he could log in properly."

Other needs

An underlying finding was the need for patients to be listened to and taken into account when thinking about improving the tool, as well as the need to know those people who work behind the PHR and to be in contact with them.

- "Are you the PHR face?"
- "Now that I get to know you, next time I´ll have a problem with the PHR, I won´t get upset thinking on you."
- "I am facing important personal problems. However, I wanted to participate in some way. I wanted to be listened."

Survey

A Survey for 1849 patients was conducted. 668 individuals answered it completely. The response rate was of 36,12%. (Table 1)

In relation to the PHR access, 61% of the surveyed answer that they did it though the institutional web page, while 33% used the google browser.

As regards the frequency of PHR´s use, 43,71% answered they used it weekly and 42,07% monthly.

The most used functionality (Fig. 1) was test results visualization (93,41%), followed by appointment scheduling (87,43%) and messaging with primary care physicians (80,39%). Among those of median use we found: Consultation requests (61,68%) and medication purchasing (51,05%). The functionalities reported as least used were: The search of health care related information (26,35%), the family group functionality (9,28%), and others (11,23%).

The most used device was the desktop computer (69,6%), followed by notebook (40,1%), cell phone (31,44%) and tablet (15,6%).

Related to the resources utilized to obtain health care information, answers were as follow: Google (45,36%), PHR health information section (35,48%), they did not look for information on the internet (26%), institutional web page (22,46%), and others (6%).

Most users admit knowing the PHR news´ section (73,8%) and it meets their interests of their interest (75%).

After the inquiries, changes were performed. Among them we can mention the increase in the icons' size according to the users' requests, and the rearrangement of the application home section.

Aside from these changes to the application, different policies were established to favour communication and accompany the change. The support system was reorganized, instructional materials were sent to users and encounter spaces with users were increased.

After such changes, the support requests though the PHR and the help desks decreased. Beginning with 160 requests/day around the implementation period, this number was reduced to 30/day, most of them related to password neglect or problems with new users, from a total of 360,000 users enrolled to PHR.

Discussion

Denial, anger, bargaining, depression and finally acceptance are stages of grief during the change process. Frustration, hopelessness and anxiety are common feelings and they require acknowledgment of the underlying pain. Allowing time to adapt to the new system, improving functionality when possible and providing good training; these are important tools to help deal with the challenges of change [17].

This experience helped us to understand the vital importance of organizing and increasing specific resources during a PHR implementation as described above. These resources include: Comunication, education, support and training, all addressed to patients and professionals. These were some of the lessons learned.

As regards support resources, the need to acquire a new help desk system and reorganize the requests in categories with the aim of optimizing resources is very important. The help desk tool that was available at the implementation period did not allow the tracking of the request orders resolved, help desk referral to other areas or direct contact with the user.

The option of using and testing the new version was only chosen by a few users. Taking this fact into account, it might have been worth developing a better diffusion of the change so as to attract more users during its optional use.

The literature reports significant challenges that could represent an obstacle for the adoption and effectiveness of the PHR, such as computer or internet accessibility limitations or the technical language commonly shown by PHRs[5]. This inquiry enabled us to understand that even if users might have regular access to information and communication technologies, a digital gap exists. It is acts as a barrier for the adoption of this tool, considering the high average age of our hospital population.

Finally, the need for patients to be listened to is important (because of non-conformity with the attention received, delays in the medical appointments administrative issues, etc.). Users have shown interest in knowing the "PHR face". This signifies that for patients, connecting a face and a name and personifying the application in some way, remains important in the virtual realm..

Many patients mentioned this aspect as encouraging them in the will to be part of the designers of the application.

The need to count on a platform serving as a communication source for users, allowing notification of new PHR functionalities or even contingency periods, have been evidenced by this research. Following our experience we are at present working with such a platform.

Conclusion

This research allowed us to know the uses patients gave to the PHR in this institution and to understand the difficulties they found in its re-design. This information constitutes the clue to motivate and accompany PHR users in the process of adoption of a patient portal, and its use as a tool to collaborate with their empowerment. During a process of implementation as described in this article, it becomes essential to count on different means of diffusion and training methods. Moreover, the supportive resource must be increased.
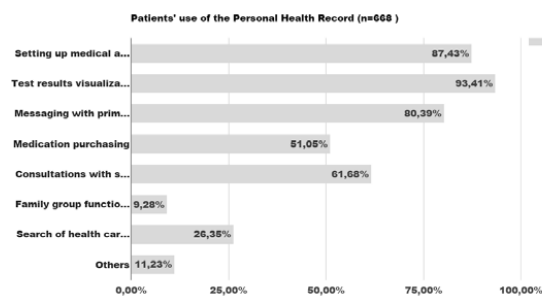

Figure 1 – Patients use of the Personal Health Record

Table 1– Survey results

Questions	%	Number of responses
How do you access to your PHR?		
Google	33,23	222
Through the institutional web page	61,08	408
Others	5,69	38
How often do you use your PHR?		
Less than 3 times a year	1,8	12
More than 3 times a year	12,43	83
Once a month	42,07	281
Once a week	43,71	292
What do you use PHR for?		
Setting-up medical appointments	87,43	584
Test results visualization	93,41	624
Messaging with primary care physicians	80,39	537
Medication purchasing	51,05	341
Consultations with specialty physicians requests	61,68	412
Family group functionality	9,28	62
Search of health care related information	26,35	176
Other	11,23	75
Which device do you usually use?		
Computer	69,61	465
Notebook	40,12	268
Cellphone	31,44	210
Tablet	15,57	104
What resources do you utilize to obtain health care information?		
Google	45,36	303
Institutional web page (HIBA)	22,46	150
PHR	35,48	237
I don't look for medical information	26,05	174
Other	5,99	40
Do you know of the PHR news section?		
Yes	73,8	493
No	26,2	175
Do you think it is interesting?		
Yes	75,15	502
No	24,85	166

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