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Value Added: needs, motivations, hopes and fears of Argentine patients about the development of their personal health records

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Abstract

The objective of the present work was to evaluate the needs, motivations, hopes and fears of argentine patients for a patient-centred personal health record development. Using inquiry methods and paper prototyping, we evaluated the different types of needs of 23 patients who were invited to take part in this study, and the characterization of the patients themselves. During the framework analysis of collected data, investigators grouped patients' needs into 11 categories (Integrated Information, Interface Flexibility, Immunization Control, Alerts, Recommendations and Reminders; Medicines; Personal Records; Accessibility; and Access to Clinical Histories and Data Privacy). The meeting with final users developed a clear shared vision of the purpose of the product and brought new insight and clarity concerning the informatics needs of health consumers. The Group Discussion technique permits that, at very early stages of the development process, users' needs can be perceived and that this, conducted before the stage of initial design, results in high performance and low costs.

Keywords:

Computerized Medical Records Systems; Needs Assessment; User-Computer Interface; Software Design; Patient Access to Records; Attitude to Health; Attitude to Computers.

Introduction

Mrs. Gonzalez, a 79-year-old with diabetes and congestive heart failure saw her family physician this morning, and on the way home she realized she had already forgotten his instructions for her new heart medication. Was it two pills once a day, or had he said one pill twice a day? She also wondered when she would find out the results of the blood test he had ordered to determine her potassium level, which she struggles to keep normal. This is a typical scenario in the ambulatory setting. Imagine Mrs. Gonzalez sitting down at her computer, logging in to her electronic personal health record (PHR) and sending a secure e-mail to her physician asking how to take her new medication, having seen that the new heart drug already was on her medication list. Next, Mrs. Gonzalez would check her in-box, open a new message, and be relieved to read that her potassium test had come back normal. Finally, she would browse the site's patient-education area and print an article on potassium-rich diets before signing off.

Since Hurricane Katrina battered the Gulf Coast, more health care organizations have begun to think about PHRs as the best way to make personal health information portable. The Centers for Medicare & Medicaid Services are exploring the creation of a national PHR for Medicare beneficiaries [1]. The Department of Veterans Affairs is undertaking a PHR project [2]. In the private sector, the number of commercially available PHR programs stands at more than 60 and continues to rise [3]. However, while personal health records are evolving quickly, research is in its infancy[4].

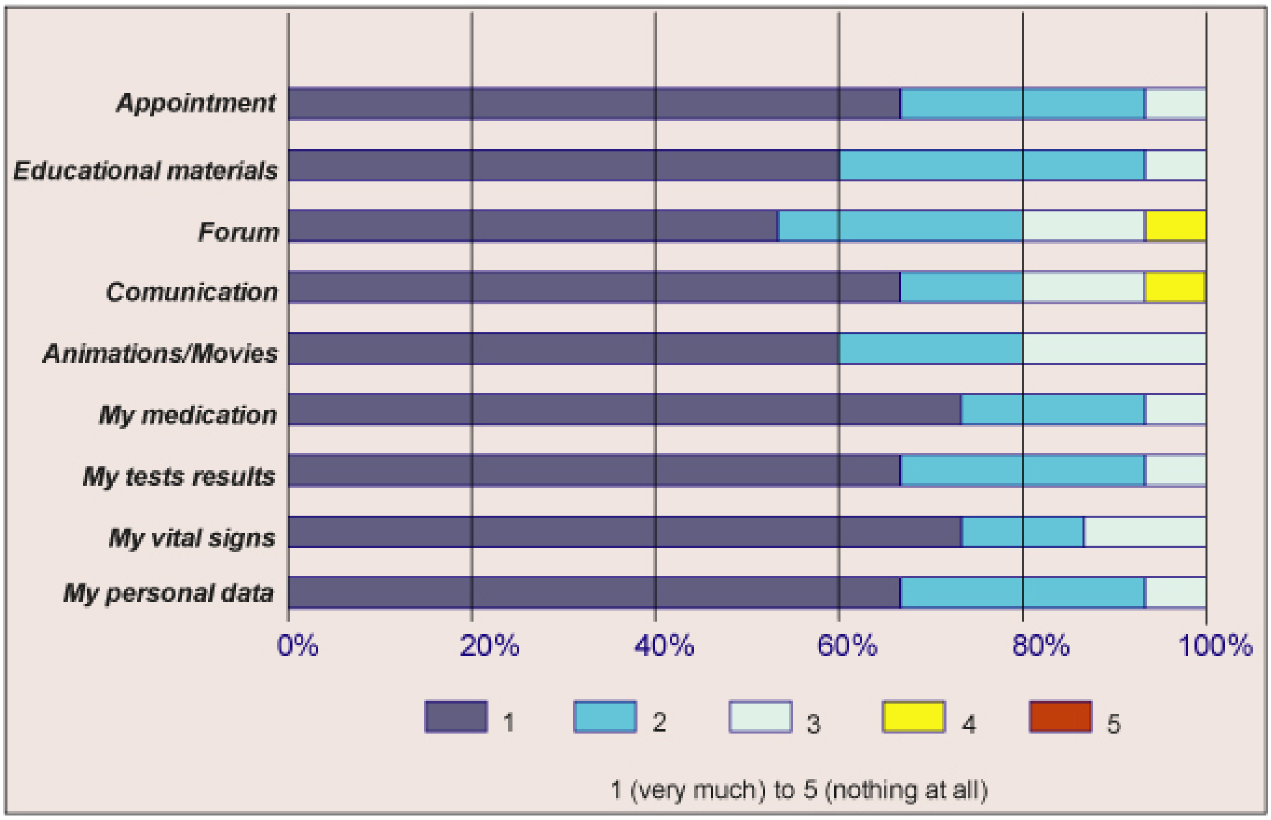
The Italian Hospital of Buenos Aires is a 650 bed non-profit university hospital located in Buenos Aires, Argentina, with more than 150,000 ambulatory visits and 3,000 inpatient episodes per month. It is affiliated to a Health Maintenance Organization (HMO) that takes care of a population of 140,000 patients.

Since 1998 a full scale Health Information System (HIS) has been gradually implemented, including ambulatory Electronic Medical Record (EMR), inpatient discharge summaries, administrative systems, scheduling systems, inpatient tracking systems, pharmacy systems and complementary studies report and visualization. Several health informatics standards have been implemented, including HL7, CDA Version 2, ICD-9CM, DRG, ICD10, and ICPC [5].

Currently we are working on the development of a PHR to support patient's access to different functionalities and services from HIS. To develop a product which will comply with the criteria of usability [6] you have to know, understand and work with the people who represent the current or potential users of the product [7, 8]. ISO 13407 provides guidance on achieving quality in use by incorporating user-centered design activities throughout the life cycle of interactive computer-based systems in an iterative process [8].

The purpose of the study was to understand those aspects of the product that are of most interest to and need for our users.

Figure 1 - Likert scale - PHR services assessment.



Materials and Methods

We based our work on methods of contextual inquiry[7]. These techniques offer the possibility of generating ideas and taking user participation into account. We specifically used Group Discussion because, even if the members of the groups have to be users of the product being studied and thus members of a context, during the session they are not in that context. Still, their experiences and impressions of the context, and their personal relationships offer information and generate ideas.

We invited patients of the HMO to participate in the activity “Internet Use: can it improve your health care?” By means of a notice published on the hospital’s web page, and in a newsletter sent monthly by post.

Two activities were carried out in two hours. After a brief introduction in which it was explained to the participants what a Personal Health Record (PHR) is, they were divided into groups so that, in 25 minutes, they could debate and write down what services or information they thought a PHR should offer. At the end of this period each of the groups told the others of its results.

To carry out the second activity, each group was given a canvas in the form of a monitor screen, and materials (scissors, markers, papers, cardboard, and stickers) and they were asked to design a portal which would provide the services and information listed in the previous activity. When they finished, each group presented its portal, explaining each of the components chosen and the function and/or information which each component should offer.

During both activities one investigator acted as moderator while another took notes. To ensure the quality of the record, the two hours were filmed and recorded.

Finally, each patient completed an anonymous survey for us to get to know details of gender, age, educational level, access to Internet, and the perceived usefulness of the patient portal components which the literature suggests, on a Likert scale of 5 points.

Results

23 people voluntarily attended, of whom 16 (69.6%) were women and 7 (30.4%) men. Only 17 people fulfilled the survey. The average age was 60.4 years and 65% had completed university studies. 88% had a personal computer with Internet access in their homes, and 86.6% use it for work, communication or topics research. 76.6% at some time sought information on health on the Internet. Characteristics of the survey respondents with regard to demographic data and Internet access are summarized in Table 1 and the results on the Likert scale are summarized in Figure 1.

Table 1 – Characteristics of Study Respondents.

	All (n=17)
Age in years (range)	59.88 (34-81)
Female Gender	11 (64.7%)
University level of study	11 (64.7%)
Internet Access	15 (88.2%)
Wide Band connection	13 (86.6%)
Internet Health Information*	12 (70.6%)
* Used internet in the past to access health related information	

During the framework analysis of the collected data, investigators identified patients' needs and grouped them in the following 11categories.

1. Integrated Information

The members of one group proposed that the portal should be problem-oriented:

"…we give priority to basic pathology" "we would like all the information about diabetes to be together" "in reality, what we want is that the information should be integrated"

They also requested that the information in the portal, on each pathology should be the product of the work of a multidisciplinary team. The following sentence reflects this:

"I don't want just to know what my clinical physician thinks; I want to know what the neurologist says, the opinion of the pharmacist, the nurse's recommendations."

2. Interface Flexibility

One of the groups insisted that guides or aids should be developed to help in navigating, and also advised that age differences should be taken into account and that the interface should be adapted to specific age groups. For example:

"We would like certain criteria to be complied with for the navigation of the portal, for example that it should be easy to change the size of the letters for those who have sight difficulties"

3. Immunization Control

All the groups suggested having an age-based vaccination calendar, but with an additional chronogram. One participant explained why this difference is important:

"It's fine to have a standard calendar with the vaccines that I have to have, but I need a chronogram that will let me agenda which vaccines I've already had."

4. Warnings, Recommendations and Reminders

All the groups agreed that having a space with recommendations on preventative practices and specific controls for each illness was fundamental. Besides, they asked for a red warning button. The difference between these functions can be seen in the following phrases:

"I ought to be able to enter somewhere and see how often I should have a mammography done" (recommendation)… *"but I should also be able to receive a warning if I have a family background of breast cancer and at my age still haven't had a mammography carried out"* (warning)

"I have everything in my diary, but I would be delighted to receive a week before, a mail or a call to my cell phone a reminder of when and where I have an appointment, be it for a visit or a study" (reminder)

5. Access to Information Sources

There was also agreement about having access to sources of contextualized information:

"We would like a section of favorites links" "that every illness should have links to pages with information that could be useful, associations, or that would put us in contact with groups of patients who suffer from the same pathology"

"We should have information available about courses, workshops or community activities" "or be able to subscribe to a newsletter with news and new developments"

6. Communication

During the pooling of ideas, all the means of communication of information technologies were mentioned.

"I have the fear that with so much technology we'll lose contact with the doctor… it would be important to have access to the e-mails of the different doctors who are concerned with my health"

"I too would like to be have access to a Chat that, if a medicine makes me feel unwell, would allow me a more spontaneous consultation"

"We need a patients' forum, a network where we feel represented, a space where we don't feel unprotected"

7. My Medicines

All the participants reiterated underlined the need to be able to have access to a section with information about the medicines that each one is using, and be able to know about adverse effects, contraindications, possible interactions with other medicines, availability in the hospital's pharmacy network, products and prices for the same genus.

8. My Results

All participants proposed the visualization of the results of complementary studies. One person suggested that it would be ideal to be able to integrate them to a request for an appointment:

"It would be ideal, if I am informed of an abnormal result of a thyroid hormone, [PHR] should be offered an appointment with an endocrinologist in the next few days"

9. My Records

Among the functions suggested, in two groups the idea came up of a space where they could see the records of Italic vital signs with the possibility of being able to complete the record with data obtained by the patients from controls in their home or in a pharmacy.

"I would like to see the controls which the nurse records every time I have a consultation" "I would also like to be able to record every time I have my pressure taken in a pharmacy or be able to record the evolution of my weight in graphic form"

10. Accessibility

In this section we group participants' suggestions which might help to optimize patient flow in the health system and service accessibility.

"We should be able to access the attention times of professionals and services because in general we find out what the possible attention times are only when we phone to ask for an appointment" "yes, and to know when one's physician is on leave, holiday, or at a congress, because in one year three different doctors attend to you"

"We should have a referenced map of the hospital, because the truth is that one has to come half-an-hour early just to find out where one is supposed to go"

"to be able to ask for appointments either to see the doctor or to have a study carried out"

11. Access to Clinical Histories, and Data Privacy

Naturally, the topic of confidentiality and privacy of data did not fail to come up.

"I would like to be able to access my clinical history, and that the doctors should have access to my portal, but on condition that I should be able to decide which doctor sees what, because there are things I talk about with one doctor while with another I feel embarrassed"

"… that the emergency doctor or the doctor that makes a house call should be able to check the details of my clinical history rapidly. I don't mean everything, but, yes, medicines, laboratories, vital signs…" "Present day doctors should go out with a computer in their hand, not a medicine chest"

The paper prototypes that the participants designed reflected the needs of the categories which we have mentioned. All the groups used the color red to make the categories Warnings, Reminders, Recommendations and Immunological Controls stand out. In spite of having been given several sheets of paper to simulate different windows, all the groups concentrated all the information on the initial screen. One of the groups put conspicuously in the middle of the screen an on-line help button to facilitate navigation on the portal.

Discussion

A meeting with the main stakeholders develops a clear, shared vision of the purposes of the product, brings new insights and clarity to the informatics needs of health consumers, such as access to reminders, recommendations, alerts, immunizations, medication, notes and vital signs, and even schedules and referenced maps.

This diversity of personal health information that participants considered relevant to PHR has direct implications for the design of new PHR tools.

It is interesting to highlight that the average age was 60 years, although this group is not consider the typically Internet public in Argentina, we found that this people use and is interesting to access health related information through Internet.

The data gathered in the Discussion Group are consistent with the standard recommendations found in the literature on the functionality of PHR. However, consumers' needs, motivations, hopes and fears add a value necessary for any successful implementation[9].

Taking these considerations into account at an early stage saves time and money, as post-implementation changes imply an enormous additional effort[10].

The technique of Group Discussion allows, at the earliest stages of development, when the requirements of the product are not firm or not completely defined, for a understanding of users' needs[11].

This methodology is easy to put into practice, does not need too many resources, and is very valuable in that it contributes to an amplification of perspectives and a deepening in a variety of considerations that, at times, pass the software designer unnoticed. In future work, we plan to design and develop a PHR that will fulfill consumers' expectations, and to invite a wide range of people to test its usability.

Conclusion

Using simple methodology we have been able to identify the needs, motivations, hopes and fears of our patients in relation to PHR and to learn some principles for the design of this new tool. But we need more research to verify how it will be used and if we can meet our usability goals.

References

[1] Lobach DF, Willis JM, Macri JM, Simo J, Anstrom KJ. Perceptions of Medicaid Beneficiaries Regarding the Usefullness of Accessing Personal Health Information and Services through a Patient Internet Portal. AMIA Annual Symposium proceedings [electronic resource] / AMIA Symposium; 2006; 2006. p. 509-13.

[2] Department of Veterans Affairs. What is the My HealtheVet Pilot? 2003 [cited December 2006]; Available from: http://www.health-evet.va.gov/

[3] Endsley S, Kibbe DC, Linares A, Colorafi K. An introduction to personal health records. Fam Pract Manag. 2006 May;13(5):57-62.

[4] Civan A, Skeels MM, Stolyar A, Pratt W. Personal Health Information Management: Consumers' Perspectives. AMIA Annual Symposium proceedings [electronic resource] / AMIA Symposium; 2006; 2006. p. 156-60.

[5] Gonzalez Bernaldo de Quiros F, Gomez A, Luna D, Martinez M, Soriano E, Staccia G, et al. Migración a plataforma web de una Historia Clínica Electrónica. In: Leão BdF, editor. CBIS'2004 - IX Congresso Brasileiro de Informática em Saúde; 2004; Ribeirão Preto-SP. Brasil; 2004.

[6] Nielsen J. Usability 101: Introduction to Usability. Jakob Nielsen's Alertbox 2003 [cited December 2003]; Available from: http://www.useit.com/alertbox/20030825.html

[7] Holtzblatt K, Jones S. Contextual Inquiry: A Participatory Technique for System Design 1993.

[8] Usability Net. ISO 13407 Human centred design processes for interactive systems. 2006 [cited December 2006]; Available from: http://www.usabilitynet.org/tools/13407stds.htm

[9] Wyatt JC, Wyatt SM. When and how to evaluate health information systems? International journal of medical informatics. 2003 Mar;69(2-3):251-9.

[10] Nielsen J. Return on Investment for Usability. Jakob Nielsen's Alertbox 2003 [cited December 2005]; Available from: http://www.useit.com/alertbox/20030107.html

[11] Creswell JW. Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage Publications: Sage Publications Inc 1998.

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