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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 and objective

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. Investigators grouped patients' needs into 11 categories. 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:

medical records systems, computerized; needs assessment; user-computer interface; software design; patient access to records; attitude to health

Introduction

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. As an example The Centers for Medicare & Medicaid Services are exploring the creation of a national PHR for Medicare beneficiaries[1].

The Italian Hospital of Buenos Aires has developed 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 [2].

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[3] you have to know, understand and work with the people who represent the current or potential users of the product[4, 5].

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

Materials and methods

We based our work on methods of contextual inquiry[4]. These techniques offer the possibility of generating ideas and taking user participation into account..

We invited patients of the HMO to participate in the activity "Internet Use: can it improve your health care?"

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 at the end 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.

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.

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.

2. Interface flexibility. One of the groups insisted that guides or aids should be developed to help in navigating.

3. Immunization control. All the groups suggested having an age-based vaccination calendar.

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.

5. Access to information sources. There was also agreement about having access to sources of contextualized information.

6. Communication. All the means of communication of information technologies were mentioned.

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 and contraindications.

8. My results. All participants proposed the visualization of the results of complementary studies.

9. My records. Among the functions suggested, in two groups the idea came up of a space where they could see the records 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.

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

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

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.

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.

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[6].

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.

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