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

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Introduction

- Health care organizations have begun to think about PHRs as the best way to make personal health information portable.
  - →Centers for Medicare & Medicaid Services are exploring the creation of a national PHR for Medicare beneficiaries. [1]
  - →Department of Veterans Affairs is undertaking a PHR project.
  - →Commercially PHRs are arising.
- However, while personal health records are evolving quickly, research is in its infancy

Introduction

- The Hospital Italiano de Buenos Aires has developed a full scale Health Information System (HIS). [2]
- Currently we are working on the development of a PHR to support patient's access to different functionalities and services from HIS.
- To comply with usability criteria is necessary to understand user needs.
- The study purpose was to understand those aspects of PHR that are of most interest and need for our users

Materials and Methods

- Contextual inquiry methods.
- We invited HMO patients to participate in the activity "Internet Use: can it improve your health care?".
  - →Group discussion about what a PHR should offer.
  - →Paper prototyping of that PHR.
  - →Anonymous survey.

Results

- 23 people voluntary attended.
  - →69.6% (16) were women.
  - →Average age was 60.4 years
  - →65% completed university studies.
  - →88% had a PC at home.
- During framework analysis of the collected data, investigators identified patients' needs and grouped them in 11 categories.

Results

- ***1. Integrated Information***. The members of one group pro-posed 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.

Results

- ***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.

Results

- ***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 History, and Data Privacy.*** Naturally, the topic of confidentiality and privacy of data did not fail to come up.

Paper Prototypes

- They reflected the needs of the categories mentioned.
- Red Color for
  - →Warnings, Reminders, Recommendations and Immunological Controls .
- Icons for web actions
- Online Help button always available

Discussion

- Meeting 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.
- The data gathered in the Discussion Group are consistent with the standard recommendations found in the literature on the functionality of PHR. [3]

Conclusion

- Using a simple methodology we have been able to identify the needs, motivations, hopes and fears of our patients in relation to PHRs and to learn some principles for the design of this new tool.
- More research is needed to verify how it will be used and if usability goals were met.

References

1. Lobach DF, Willis JM, Macri JM, Simo J, Anstrom KJ. Perceptions of Medicaid Beneficiaries Regarding the Use-fullness of Accessing Personal Health Information and Ser-vices through a Patient Internet Portal. AMIA Annual Sym-posium proceedings [electronic resource] / AMIA Sympo-sium; 2006; 2006. p. 509-13.
2. Gonzalez Bernaldo de Quiros F, Gomez A, Luna D, Martinez M, Soriano E, Staccia G, et al. Migración a plata-forma 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.
3. Wyatt JC, Wyatt SM. When and how to evaluate health information systems? International journal of medical informatics. 2003 Mar;69(2-3):251-9.