Prototyping a Personal Health Record Taking Social and Usability Perspectives into Account

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Abstract. This paper presents the process of design involved in prototyping a Personal Health Record (PHR), a patient-centered information and communication hub. As the PHR has to be used by laypeople, we focused on their health related activities (i.e. information management) carried out in the household using a sociological perspective to elicit the infrastructural requirements of the IT. We identified three distinct document management strategies (zero effort, erratic, networking) and 'translated' them into three design characteristics: flexibility, adaptability and customizability. We argue that the key to such PHR success is its capability to support the existing activities carried out by laypeople in managing their health record.

Keywords: Personal Health Record, SOA.

1 Introduction

Healthcare sectors in western countries are facing a worsening shortage of personnel and constant growing costs. A rising demand for cure, associated with an aging population, requires new organizational solutions to maximize the efficiency of the whole system. These problems are faced also through the adoption of ICTs so to reduce medical errors and increase inter-organizational efficiency and inter-organizational coordination [1]. Still, so far, technologies such as the Electronic Medical Records (EMRs) have failed in creating an integrated healthcare provision as rarely these systems communicate [2].

While research on EMRs' is still a major issue in medical informatics, in the last years there is a growing interest for technologies that address the healthcare sectors' problems proposing to empower patients. Personal Health Record (PHR) is among these. PHRs are electronic patient-controlled hub of information that should allow the individual (or a family member) to access, manage and share their health information [3]. An ideal PHR should support the individuals in their health-related activities through all their lives, adapting to their evolving needs. At the moment there are very few fully functioning PHR system but there is a growing production of different prototypes. Still, even a superficial analyses of the ongoing debate on PHRs shows that there's a strong optimism that relies on the foreseen enthusiasm of laypeople to use this technology. It is clear that this foreseen willingness to adopt a PHR is part of the rhetoric of innovation. To our knowledge, though, few PHRs have been designed after an analysis of what people actually do to manage their own health [4].

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We assume here that just like EMRs are designed having in mind the workflow and the needs of the medical personnel, PHRs need to take into account the multifarious ways and settings in which the individuals are more likely to use them. At the same time, these systems need to be easily usable by anyone. In this paper we'll present a prototype of TreC, a PHR sponsored by the Autonomous Province of Trento, a local government authority in northeastern Italy. TreC has been designed according to the principles stated above. Data model and architectural components have been chosen after a sociological inquiry about the strategies adopted by laypeople to manage their health information in the household and the analysis of the literature on usability.

2 Personal Health Management in the Household

The project started with a research aimed at eliciting the real activities carried out by people to take care of themselves and their perceived hierarchy of relevance. We focused our attention on the health information management, the 'invisible work' [5] people are supposed to do in order to communicate with their doctors, with the purpose to identify the strategies commonly adopted.

2.1 Methodology

We analyzed health information management of 30 families conducting ethnographic interviews [6] in their houses. The context of the interaction allowed to combine in-depth interviewing with ethnographic observation. The respondents agreed to show us their medical archives and the places of the houses were they were kept. Interviews (50-80 minutes) were audio recorded and transcribed. Transcripts were coded using a grounded theory method [7] and analyzed using Atlas T.I 5.5 software.

2.2 Three Strategies of Health Information Management in the Household

We analyzed the interviews in search of common elements people use to justify the ways they keep medical archives. Four concepts emerged: existence of a classification system, foreseen use of information, perceived importance of the information, and network of caregivers (formal or informal) which would access the documents.

'Classification system' refers both to the actual existence of a way to sort documents out and to its mutability in time. 'Use of information' is the frequency of access to archives, to share information with their doctors or for personal interest. The "perceived relevance", as opposed to the actual use, is the foreseen use of the information. Finally, the "network of caregivers (formal and informal)" refers to the people with whom the documents in the archives are shared. The combination of the four dimensions led us to identify three strategies in health information management.

A "zero effort strategy" is the most adopted. Health information management is simply a record keeping activity without any perceived usefulness of the records kept. Documents are not classified but simply kept randomly (e.g, all in a drawer), people do not browse them in search of information nor their doctors ask for them once again, and people are not able to tell if they are going to be needed. As they are not considered relevant, people do not consider a priority to make them easily accessible.

Table 1. Three personal health information management strategies

	Zero-effort strategy	Erratic strategy	Networking strategy
Classification system	Random and long lasting	Analytical and mutable	Analytical and long lasting
Use of information	Rare/null	Frequent	Medium
Perceived importance	Low/null	High	High
Network of caregivers	One doctor	More than one professional caregiver	A network of informal caregivers

An "erratic strategy" is characterized by an analytical classification developed to keep the interaction with the doctors running smoothly. People and doctors both consider highly relevant the information stored. Documents have to be re-ordered frequently to use them in the relationships with more than one doctor as each of them is interested only in a sub-set of data. Moreover, the evolution of the disease may suggest a different classification to better suit the need of the moment. The constant use of these data requires them to be easily accessible at any time.

"Networking strategy" is adopted as a part of a shared support for elderly or disabled people. Documents are sorted out in order to provide the relevant information in emergency. Moreover, health records are placed so to be accessible to a given number of informal caregivers (e.g., sons and daughters of an old parent) so that any of them can gather information (e.g. to manage a medication scheme).

These strategies are not mutually exclusive. Rather, many people adopt more than one at time for different records. A cancer patient, for instance, would use an 'erratic strategy' for this disease while keeping a 'zero effort strategy' to manage other, less relevant, health records.

2.3 Implications for System Design

As people may use more than one strategy for health information management the system has to be flexible, allowing users to decide which information is relevant and how to create connections between documents. While a 'zero effort' strategy merely requires the documents to be stored, an 'erratic' strategy can only be supported by making the system flexible enough to be adapted to the unpredictable changes in one's health. Moreover, people have to be given the opportunity to customize their system adapting it to the needs of the moment just as they do with their paper records. Finally, the observation conducted while interviewing allowed to see that the relevance of some health document was stressed by strategically placing it in different places in the house. People keep prescription by the entrance door of the house became to remember to buy medications; they keep calendars with (also) medical appointments in the corridor to coordinate the social activities of the family; they keep their diabetic booklets, glucometers and insulin in the kitchen so to manage their diabetes. A (future?) requirement of the system is to be pervasive, so to make the information available where it is needed and used.

3 System Design

The ethnographic study (see Par. 2) identifies three strategies adopted by people in the management of the information about their health. The necessary conditions for the realization of these strategies are translated into design characteristics: flexibility, adaptability and customizability. Flexibility is the ability of a system to support individually tailored and ad hoc solutions while adaptability refers to the system capability of evolving in order to satisfy ever changing requirements. Customizability allows users to choose which functionalities can better accommodate their habits and preferences.

The sociological analysis focuses on how people organize their paper documents which are only one of the media through which health information is vehiculated. We believe that previous considerations can be safely generalized to every kind of health information. In other words, the system must be flexible and adaptable so that users can choose which kinds of information and functionalities are relevant with respect to a particular need in a period of their life.

The design of a PHR should support people in managing their health and organizing their activities. Thus we believe that a PHR architecture should be aligned to general strategies people spontaneously adopt and invent in real life for the management and organization of their own health. In other words, designing a good architecture for a PHR is more related to the aspects of social organization of work than to IT world and its buzzing words.

Nobody doubts that an IT system for a PHR must be secure, reliable and interoperable. These qualities are necessary, but not sufficient to define a PHR. In addition, smarter people have already discussed for a long time in the literature on how to make IT systems more secure, reliable and interoperable. Thus we will not deal with these technical topics here.

3.1 Design Principle

A design principle is an architectural paradigm for information organization that should support some design characteristics in a system. In this section we describe the design principle we followed in the definition of the system reference architecture. The underlying assumption is that the principle should drive the system towards the three design characteristics emerged from the ethnographic study.

The system is organized in three levels of abstraction. The first level describes base functionalities, that is, the bricks which can be assembled to build more complex functionalities. Base functionalities are agnostic in the sense that they do not know their context of use. For example, a web service with a CRUD (Create Read Update Delete) interface managing the list of currently taken medications implements a base functionality.

The second level is the configuration level. A configuration is a collection of functionalities which act together in order to realize a use case and respond to specific health needs. Configurations represent contexts of use. For example, the set of services for the management of a chronic disease is a configuration.

The third level is the control level. The control level defines the rules a configuration must satisfies (e.g. people privacy is a priority) and describes how evolution from a configuration to the next one is carried on. Customizability lays in this level, too.

The design principle is based on the observation of what changes more often in a PHR during the life of a person. While functionalities are quite stable, configurations are mutable because they reflect health needs which are volatile and dynamic. The modularity of a configuration makes the system more adaptable and flexible.

Coming back to examples presented in Section 2, a use case may correspond to a health problem, for example a chronic disease or aging. Health problems entail some needs such as the necessity to make information more accessible. A configuration is a collection of "tools" whose functionalities help people to sort out documents. The three strategies identified above are just requirements a configuration must satisfy to support a use case. The evolution of a disease may trigger new needs, hence components of a configuration should be substitutable with others that better fit the new context.

3.2 Architectural Components

The design principle is implemented at two independent levels of system architecture: presentation layer and service layer. The former has to do with human-computer interactions. The latter defines how atomic and composed functionalities are organized.

A service is a functionality indentified in and implemented by an autonomous piece of software. Services can be composed in more complex and specialized services. Services are indentified with a middle-out strategy [7] from case studies and high level functional requirements (e.g. HL7 PHR [8]), consolidated data models (e.g. PHD [9]) and from legacy systems (e.g. national health infrastructure and regional clinical document repositories).

An application is a service that presents a view of the system to humans. An application uses some services of the PHR and (possibly) some services developed by third parties. For example, if an application shows epidemic data over a country, it merges PHR services and map services of an external geo server managed by a third party. Applications can be designed also to accommodate specific needs (e.g. people affected by diabetes).

In this phase of the project, we are focusing on the development of a web application to allow an heterogeneous group of people to access basic PHR functionalities. The application follows a classical three-tier architecture and is a portal that aggregates widgets and offers some common basic functionalities (e.g. single sign-on). A widget is a self-standing application that lives within a web portal. Widgets are agnostic, that is, they do not know why and in which context they are used.

3.3 Underlying Data Model

The underlying data model of our PHR consists of four domains. The first domain is inspired to Project Health Design data model [9] where users are active actors in the management of their health and can generate information flows towards health providers. The domain is divided in three sub-domains: observations of daily living (e.g. glucose measurements, pain description, drug administration), medication management (e.g. list of currently taken medications) and calendaring (e.g. task and event scheduling). The second domain contains concepts modeling clinical resources and communication from and to healthcare operators; clinical records and messaging are

part of this domain. The third domain captures all the concepts related to current health status and personal health history; involved concepts are close to attributes of the Continuity of Care Record. The last domain models user preferences and advanced directives.

4 Future Work

The ethnographic study described before gives us useful suggestions for outlining the structure of TreC prototype. The ongoing work is to design the TreC user interface so that not to compromise the user's acceptability, strongly influencing the use of the system. This section focuses on some remarks about usability of TreC user interface and older people as target user. Accessibility aspects with respect to user disabilities are out of the purpose of this section.

4.1 The Usability Evaluation Approach

From a conceptual point of view, usability evaluates the distance between the design model and the user model of a product. The design model describes in detail the structure of the system and how the system will be implemented. The user model refers to the operation model worked out by the user. It leads the way him/her interacts with the system. The more the design and user models of a system are close, the less the system is awkward to use. So the system interface is critical and need attention. Generally speaking, a good interface should answer for resources, limits and instructions for use; a lot of attention should be given to the relation between what a user could do using the interface layer (i.e. moving object, writing, etc.) and the following results.

The aim of a system's usability evaluation is to understand how well a system communicates with and support the functional needs of its target users. There are a lot of usability evaluation methods described in literature. Each methods can be chosen according to the usability elements we need to look into (i.e. learnability, efficiency of use, memorability, error prevention, and satisfaction) and gives better results with real user participants. Experts recommend using a combination of techniques according to research needs during the system design and development lifecycle.

4.2 The Target Users

Population aging is a long-range trend that characterizes affluent society. Life expectancy is longer than that in the past and there is a substantial increase in the number of older people (age 65 and older). Older people usually have more long-term health problems, chronic illnesses (such as arthritis, diabetes, high blood pressure and heart disease) than younger people. Moreover they consume more prescription and over-the-counter (OTC) drugs than any other age group. So even though TreC is designed to be a universal system, older people are the actual potential user group.

Besides this consideration, literature about universal usability issues suggests to focus specifically on the needs and functionalities of older (and disabled) people. In particular Newell et al. underline that "*in terms of their abilities, design which is*

appropriate for older people will be appropriate for most of the population, whereas design for younger and middle aged people will exclude significant numbers of older people" [10]. For all this reasons we decided that older and disabled people would be the target user for the designing and development phase of TreC.

4.3 Implication for the System Interface

Technology could be used to approach and deal with most of the problems related to aging. In particular, smart system like TreC could empower older people in managing their health. But during the design phase we have to keep in mind the special needs of elderly people in terms of implication of age-related changes in functional abilities. In fact they face technology usability impediments related to physical, mental, and cognitive impairments. Moreover, considering the historical spread of technology and internet at work and then at home, current older people are unlikely to have experience of computer or internet use.

Usability literature make specific individual recommendations in terms of product attributes in order to face all these problems: font size, use of background and text color, etc. Nevertheless building a user interface on such recommendations is not enough. The composition of such interconnected elements may hide new usability problems that could be noticed only during a usability testing session. So in the design phase of TreC interface we have to consider the suggestions coming from the usability literature. The next step is to rebuild the interface with a pleasure graphic. Then usability testing with older people will allow to check the whole user interface. The results will be translated to appropriate input for the user interface design.

5 Conclusions

In this paper we have described part of a process aiming to design a PHR as patient-centered information and communication hub. We argue that the key to its success is its capability to support the existing activities carried out by laypeople in managing their health records. In this perspective, the identification of user requirements can be only elicited through the analysis of the current management strategies used by laypeople. Document management strategies are interpreted as software qualities supported by a highly modular architecture following the service-oriented paradigm.

In the next phase of our work we will devote a particular effort to early identifying usability problems that may impair the use of the TreC system. After building the user interface by giving it a pleasure graphic, the involvement of older people for carrying out interactive usability testing on refined interface versions represents an effective way for achieving this.

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