

# INTEGRATION OR SUBSTITUTION? EVALUATION OF A PERSONAL HEALTH RECORD

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*Personal Health Records (PHRs) are web-based systems that allow patients to access, manage and share health information. In this paper we present the evaluation of the trial of a PHR in a province of northern Italy, which allows citizens to receive documents from health facilities (e.g. lab tests) and to keep a structured health diary. The analysis conducted through semi-structured interviews revealed the emergence of new management practices of the official health documents and a substantial disregard of the functions of a diary, in addition to continued use of information management tools designed by the users.*

*Keywords: Personal Health Record, personal health information management, qualitative research, paper-based records.*

## **1 Introduction**

Health is a sector where for several decades we have seen the steady-paced introduction of new information and communication technologies (ICTs). Typically, this process involved the creation of electronic tools for professionals (doctors, nurses, clerks). In recent years, however, we have witnessed the development of systems designed to be used by citizens/patients in a logic that would like them to be more and more involved in the processes of prevention, monitoring and care. In this paper we deal with the evaluation of one of these technologies, a Personal Health Record (PHR), a web-based tool that allows patients to access, manage and share medical data produced by health facilities (e.g. medical records, reports about diagnosed medical conditions) but also personal characteristics like age and weight or habits (Markle Foundation 2003; Halamka, Mandl, Tang 2008; Weitzman, Kaci, Mandl 2009). In the last years these patient controlled records have attracted the attention of both the scientific community and the industry for their potential benefits in becoming a key element of new forms of healthcare delivery.

In the rhetoric of innovation such tools should enable patient empowerment, increasing awareness about his/her own health whilst supporting him/her in its management. Some recent work (Moen & Brennan, 2005; Unruh & Pratt. 2008; Zanutto & Piras, 2010), however, let us assume that the acceptance and willingness to use new electronic tools can be difficult because in everyday life patients enact complex management practices of health information not easily reproducible through an electronic system.

## **2 Research context and objectives**

This work is the first evaluation of a PHR system being tested in a small province in north-east Italy (about ½ million inhabitants). The system was designed and developed from an analysis of health information management practices by citizens which are reported in other works (Piras and Zanutto 2010; Piras et al. 2010). The beta version of the PHR was released in July 2010 for a trial in a context of actual use but on a limited amount of users, according to a logic of testing widely adopted in living labs (Følstad 2008).

The system consists of a web portal through which users can access a restricted area through a system of strong authentication (one-time password via mobile phone). The system offers user two macro-functionalities. The first is access to all personal documentation produced by public health facilities (e.g. medical reports, laboratory tests, discharge letters) and the ability to add "tags" or "notes" to each document. The second feature is a structured health diary in which to keep track of events, data or personal information (e.g. family clinical history, list of medications taken, self-measurement of clinical parameters).

For the duration of the trial the 500 system users were guaranteed unmediated access to clinical information produced by health facilities without a medical filter. This has allowed citizens, for example, to have medical reports and laboratory tests at the same time as their general practitioners. People involved in the trial were selected through different channels: members of patients' associations, patients invited by their general practitioners, people that took part to the pre-design studies and their relatives.

The purpose of this first evaluation of the system was to determine if and how people change the existing management practices of health data and how they react to information which is not filtered nor mediated by health professionals.

### **3 Methods**

The research was carried on through 15 semi-structured interviews conducted with users who had made the highest number of accesses to the system (detected through the log files on the server). The choice to focus on early adopters of the technology is justified by the desire to understand what are the most attractive features of the system and what directions to take for future development. Respondents were 8 men and 7 women (3 under 35, 4 in the age group between 36-55 years, 8 over 55).

The interview layout was structured to investigate four macro-topics: most commonly used features, moments of intensive use, criticality elements or satisfaction in the use and suggestions on the future development of the system.

The interviews (average duration of more than half an hour) were transcribed and the interview layout was used as a preliminary analysis grid. Subsequently, based on the initial analysis, further processing was carried out to highlight some recurring elements: the use of self-produced information management tools and non-use of some features of the system being tested.

### **4 Results**

Analysis of the interviews allowed us to observe how, in real-use practices, the PHR has allowed users to go beyond the use assumed by the research team and the development in the design phase and, at the same time, how only some features of the system have actually been used. Furthermore, it has also been noted how the interviewed users have kept management practices of personal health information unchanged using other tools (paper and electronic) with respect to which the PHR went side by side without replacing them. Below we give account of the main results.

#### *4.1 Access to clinical results in real time*

For all respondents the primary reason for using the system was the ability to view the results of clinical tests quickly without waiting for the mail delivery or collection in person. All users have expressed considerable interest in the fact that the information was readily available online and almost all (14 out of 15) said they carry one or more accesses to the system on the same day of the examination to check if the results were available. A paradoxical effect of the ability to access their own data in real time was manifested in the case of a young interviewee who used the system during a hospital stay to assess (and challenge) the performance of doctors in the department.

#### *4.2 The PHR to manage and expand the network of carers*

The possibility of having clinical documents in electronic format has been used by some respondents to convey their information more quickly within their network of clinical care. The availability of paper records alone made their share possible only after some work (e.g., scanning, photocopying, hand delivery) or involved the use of resources not always available (e.g. fax). The immediate availability in electronic format has allowed more rapid sharing with physicians via e-mail (at least with those who accepted this new form of interaction with their patients). This choice was found to be linked to three reasons: to request an opinion to assess the need for a visit, offering a doctor the chance to see the medical tests before a scheduled visit, get a second opinion from a new doctor. Along with these reasons, some respondents said they had shared documents with relatives doctors or nurses to have suggestions or references.

#### *4.3 Use of the system to access medical data in different places*

One of the system's most popular features was to be able to avoid having folders containing paper documents always with them. Particular appreciation was expressed by respondents with a rich medical history who travel frequently and were used to carry a selection of medical records in order to provide accurate information in case of an emergency. Two respondents, for example, regularly spend part of the year (up to 6 months) in a holiday home and at the beginning of the trial they chose to leave the significant amount of documents that they used to bring with them in the main residence.

#### *4.4 The persistence of other tools of personal health information management*

The PHR system availability has not substantially changed the habits of the investigators in the production, storage and management of self-monitoring health information. Some users, well before the start of the experiment, equipped themselves with simple tools to support their health condition. For brevity we give the following accounts of two cases in which these tools are either paper (the first) or electronic (the second).

##### *4.4.1 Paper-based headache diary*

One interviewee had created her own "diary of the headache" consisting of a monthly calendar (A4 print from a Microsoft Word calendar) in which, at each day, she kept track of symptoms, events she thought were associated with the onset of pain (e.g. menstrual cycle, patterns of stress) and painkillers taken. The information contained in this paper diary were not shared with her doctor, who was not even aware of this tool, but they were used by the interviewee to keep track of the evolution of pain, to try to understand the factors of the onset and to make decisions regarding her own condition. The diary was kept in the kitchen and used only at the onset of pain.

Although the PHR system being tested would allow to enter all the information contained in the paper diary the interviewee chose not to use it, after making an attempt, because of the more cumbersome steps to be performed (must turn on the computer; fields to be filled are not all on the same page, the system does not accept abbreviations which she is accustomed to use). Another reason given for not using the system to replace the paper diary is that the former does not provide a synoptic overview of the trend of the condition for the last period and it is effectively useless as a forecasting tool.

##### *4.4.2 Computer-based medication scheme manager*

Following a serious problem, the wife of an interviewee has remained partially disabled and reliant on her husband help for the management of daily life activities and her therapy. This is based on the assumption of a large number of drugs. The respondent, who at the time of the onset of the disease did not have any computer literacy, created over time a basic management tool of medical supplies thanks to a spreadsheet (Microsoft Excel) through which he can quickly extract some information

about his wife drugs needs used, for example, to know the number of boxes of each product to be prescribed before going on holidays.

In this case the user immediately realised the inability to use the PHR system for these requirements. While showing interest in the functionality that lets him keep an updated list of medicines used by his wife, the absence of specific tools for managing the home pharmacy made it impossible to replace the adopted system. Besides, in this specific case, the simple spreadsheet had a symbolic value that transcended the practical usefulness of the system as it represented for the respondent the outcome of learning the use of the computer in an advanced age.

## **5 Discussion: integration, not substitution**

The analysis of the interviews showed how people have perceived the PHR system primarily as a useful tool to access and manage medical records produced by health care facilities (e.g. laboratory tests, discharge letters). The availability of the system allowed not only to perform faster some of the tasks usually associated with managing healthcare records (i.e. sharing them with the doctors) but it also gave rise to opportunities to play the patient's role differently (e.g. challenging medical decisions during hospitalization, engaging parents with medical expertise in the network of care).

On the contrary the interviewees have not considered the system under evaluation particularly suitable for collecting and managing self-produced information about their health or used for strictly personal objectives. For the latter respondents continued to use systems (paper and electronic) already personally developed and considered best suited to their own needs.

A first level of interpretation concerns the radical difference of the recipients of the information contained in various documents. For clinical documents, although the Italian national health system gives citizens the right to have them, the real target audience is physicians and health care institutions. The information is standardized and designed to be viewed by any professional in different settings. It does not come as a surprise, then, that a tool that makes it faster and less costly to receive, access, sort out and electronically transmit may be adopted by users. In other information management tools (e.g. the two shown above), however, the producer and user of information coincide with the patient himself. In this case, the essential elements are not standardizing and speed of transmission but rather the ability to store and display only the data deemed important by the individual user, the easiest thing to achieve on their own rather than in a system designed for the use of a "generic" user. In these personal health-related activities, moreover, the content of information might change over time depending on the circumstances and self-produced information management systems appear to be more flexible and easily adaptable to the situation at hand.

The second level of interpretation concerns the practices of use of the various documents. Research has shown that "official medical records" do not belong to the everyday life of the patient, with the exception of the acute phases of illness (e.g. hospitalised patient). This leads to the rarified use of documents and to a management oriented towards the need to share them with medical carers (Zanutto & Piras 2010). The health-related self-produced information, however, are managed favoring their continued accessibility and immediacy of use. The analysis shows that any artifact that requires mediation in labor time of transcription and/or recording of values soon led to the abandonment of automated systems. The materiality of the paper objects, for example, binds very well with the immediacy of their use in data recording practices in which even the powering time of an electronic device or connection to the Internet can be daunting. This also calls into question the level of integration with the places of everyday life. It is no coincidence that some of these self-produced tools are attached to the refrigerator with a magnet or are in a cabinet in the kitchen. The places, as outlined by our fieldwork, are essential elements to consider in the affirmation of information systems.

In conclusion, research has shown that users have regarded the PHR under evaluation as a tool to supplement and not to fully replace their own information resources. This behavior observed in user that took part to the trial shows significant elements of similarity with what occurs in the

computerization processes in organizational contexts, where we see a persistence of “low-tech” information systems (e.g. fax, phone, spreadsheets, paper records) next to systems that were designed to replace them (Sellen & Harper 2003). The latter often appear to have a greater ability to support context-specific practices.

The overall results provide two stimuli for reflection on the design of patient-centered health information systems to be further explored. The first is the possibility of studying forms of integration between different information management tools, accepting the diversity of needs and being confident in the user's ability to integrate them in a variety of practices with different timing and purposes. The second one is to take advantage of more recently created devices (e.g. smart phones and tablet PCs) that combine portability, ease of access and use and a growing number of applications (apps), often self-produced and in any case easily achievable to support very specific tasks. In both cases the research suggests that personal health information management, at a close look, might reveal to be far too complex to be supported by a single tool, no matter how useful for some specific purpose it might be, but it can benefit from the coordination of different resources.

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