

PHR governance requirements leading to patient selection

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Abstract. Personal Health Record (PHR) projects have been supported in recent years by several health institutions. The aim has been to involve patients, the idea being that patients must become more significant in health infrastructure policy. The paper presents some results concerning a PHR system implemented in a region of North Italy. The system has been active since 2011, and more than 10% of the region's residents use it. The purpose of this paper is to highlight how an extensive PHR infrastructure planned for everybody has become an interesting "tool" for specific intensive health situations. Drawing on the results of 20 interviews with the most frequent users of the system, we have identified three categories of users: individual or family health controllers, therapy driven managers, and complex illness managers. These diverse ways to adopt the infrastructure only partially meet governance expectations.

Introduction

A PHR system is a web-based technology that allows all its users to manage, share, and access medical information. Originally it was conceived as a tool to keep a personal network of formal/informal caregivers active, but it was also considered an instrument to help create a new doctor/patient relation (Markle Foundation 2004). Despite this optimistic scenario, however, PHRs have developed a complex new scenario among health infrastructures. Healthcare managers and policymakers, the main sponsors of PHR systems, are convinced that a design for all patients should be the main aim. The economic crisis in Western societies has generated two opposite effects regarding eHealth

investments. On the one hand, governments are investing in more efficient infrastructures for health systems, often supporting centralization and connections among many different systems. An opposite effect is the proposal of extensive infrastructure projects that unfortunately reduce the interest of citizens who use them (Greenhalgh *et al.* 2010). Recent studies exploring the evolution of these systems suggest that design has often failed to give a new functional infrastructure to basic and common services. It has more often happened that some functionalities have been adopted, but only a few patients have used them. Or people simply do not find the system useful for what the design was developed to achieve, and use it for other purposes. As Davidson and colleagues (2015) have shown, PHRs have shifted their objectives from a general and nationwide approach to single issues and single medical institutions. Similarly, PHRs have changed from being communication tools intended to enable close interactions between patients and doctors to more distant monitoring tools. As stated by Piras (2016), the patient side in data management displays a range of many different things like “Patient-Generated Health Data”, “Observations of Daily Living”, and “Personal Health Information Management”. This is one of the reasons why, after the adoption of PHRs system, something in the field has changed and we can observe some unsuccessful targets and the affirmation of other aims (Davidson *et al.* 2015). The paper explores how the changes incurred from the design phase until deployment and thereafter have intercepted the patient’s needs, and which kind of data use has been generated by the interaction between patients and systems.

Empirical studies show that patients want to exercise control on their condition, and this purpose induces them to manage decisions in the first person, sometimes without consulting doctors (Civan *et al.* 2006; Halamka *et al.* 2008; Moen and Brennan 2005).

Infrastructures play a strategic role in this relationship. On the one hand, they allow people to access more information; on the other, they seem to reproduce the ‘physical’ world. This means that the infrastructure design is driven by the physical display of buildings, services and organizational hierarchies. Hence patients have new opportunities to use their data as the system changes the materiality and the flow of some services. But, they are again pushed to the periphery of the system and not involved in the design and implementation phases (Davidson *et al.* 2015).

Research design

The system discussed by this paper is a web-based PHR that has been monitored with a long-term program (2011-2016). The PHR is owned by the regional administration, and it was designed and developed by a publicly-funded Health IT Research Centre. The basic purpose was to replace the existing paper-based

diagnostic tests delivery system, which required patients to return to the hospital to obtain their medical results. The PHR collects electronic copies (usually PDF) provided by all public or private sources of diagnostic tests, laboratory tests, diagnostic services, hospital discharge letters, and results from almost all medical services belonging to the regional public health system. Hence, when a health problem arises and the GP sends the patient for a medical test or specialist examination, after the access, the system usually sends all the results in this repository within a few hours and, at the same time, an alert by email. These alerts sent simultaneously to similar alerts sent to the family GP patient repositories. This solution, adopted by design, despite being appreciated, also generate some minor troubles. Patients, after they have received an alert, expect that their GPs have immediately had a sigh of them.

When patients access the system, they access a wide range of applications. They can view their tests, but also the payments procedure, the appointment booking service, a procedure to change the family GP. The system also allows users manually to insert other personal health information (i.e. drugs, temperature, blood pressure, intolerances, and other measurements provided by personally owned instruments). From this perspective, the PHR is also an instrument, and perhaps a symbol, of the local healthcare system built around the citizen/patient (Halamka *et al.* 2008).

Among the population, after some institutional advertising campaigns which lasted over four years, the system was ‘opened and it has been used at least once by 60,000 people. For our research, we selected those who had used the system at least three times, assuming that theirs was not just ‘exploration’ but real use.

After a quantitative online questionnaire answered by 15,000 (50%) respondents, we decided to select 20 of the most frequent users for face-to-face interviews, for the most part in their homes. Ten most active users were selected considering the entire system activity period (from 2011); five were selected in the previous year and five in the previous six months. It was important to consider both long term users and recent users to avoid any bias due to an intense use determined solely by a specific problem.

In the interviews, we asked the respondents to describe: i) how they interacted with the system, how complicated it was to start, what ‘help’ was provided, what future developments should be adopted, and finally how they felt as citizens involved in this system. Adopting a qualitative research design, we wanted to investigate perceptions and use of the system. We used a contextual interview methodology. During the conversations, we collected information on diseases, everyday use, tricks and problems resolved to adapt the system to their expectations. The project’s stakeholders were also interested in monitoring how much they appreciated the functionalities, and what new functionalities were most expected. We recorded all the interviews, and the transcriptions were analyzed using the template coding method (King and Brooks 2015).

‘Personal’ challenge versus ‘public’ designed infrastructure

The first finding of the analysis was that, as the monitoring progressed, patients using the system did not precisely represent the population of the region. Indeed, most of them were well-educated or affluent persons of high social status. As regards the distribution of ages, the system’s users were overrepresented in ages around forty, underrepresented in youngest and oldest ages, and overrepresented in the central ones. After a general quantitative account, we started to code the transcriptions. Working with the excerpts from the interviews, we identified a typology of three non-exclusive styles of use.

1 *Individual or family controllers.* These users were interested in the system mainly in order to have constant access to diagnostic tests made available by professional providers through the infrastructure. This style was associated with the need to control bodily parameters on a regular basis, especially when patients had to be monitored and the burden was shared among several family members. For example, this was the case of elderly patients managed by sons and daughters responsible for conducting simple analyses to monitor the situation. Such users probably represent those who fitted the original purpose of the design. Once system access was established, it became an everyday service and a tool to organize health assistance. These users appreciated the functionalities and every new feature of the system. Moreover, it is significant that this enabled them to avoid intense relationship with health professionals.

2 *Therapy driven managers.* These users had severe but stabilized illnesses. The role, performed by these users, is to be continuously working on a specific therapy. Some used the system to check blood viscosity, for example after heart disease, to understand and establish a regime of medication to stabilize and improve their health. Usually these users considered the system to be a specific tool (like a thermometer). They were not interested in adding personal data to the system, since the functionality was well accepted and combined with new practices developed around the technology by health professionals and patients alike. There is evidence that patients, in this way, are happy to be in contact with professionals and can suggest drug management to doctors themselves. In addition, the system is often able to help geographically dispersed families to share information on relatives.

3 *Complex sickness managers.* This group of users comprised patients suffering from severe illnesses who required intensive treatment. These patients’ illness affect also family relatives. Quite often if someone was suffering from cancer, or a complex pathology, especially with ambiguous symptoms, the system became a ‘working-around platform’. Users collected diagnostic tests to ask for a second opinion, or to monitor the development of unexpected symptoms. What is quite clear is that these users were not at all satisfied with some of the system’s

functionalities. In fact, as a regional public infrastructure it is not connected with other regional health systems. Only recently has a national mandatory protocol required every regional infrastructure to provide specific parameters to help systems share information. This evidence from the field shows how systems are adopted and integrated into practices. On looking closely at these practices, objects seem to change their functionalities and relevance to patient trajectories between different infrastructures.

Discussion and conclusions.

Data management is related to infrastructures in the sense that the latter require peculiar work by the patients. Moreover, their presence and adoption by users change the perception of both health system performance and quality in therapy management. The infrastructure used changes knowledge of health practices and health systems. Although administrations are looking for the ‘true’ PHR with which to innovate the health system, it has been found that infrastructures are knowledge sensitive and require skills for autonomous data management (Fortin and Drazen 2012). This is the reason why selected users from the general population play the most active part (Halamka *et al.* 2008). Day-to-day requirements are easier and simpler if an infrastructure can simply reduce the waiting time for a diagnostic test. As Moen and Brennan (2005) have shown in this regard, specific treatments are considered as less important than data. A patient considers it much more important to stay in close contact with his/her health data after, for example, a medical test results than a specific access to a visit for a treatment.

As we have seen, the implementation of this regional patient-centered infrastructure engenders new patient practices, whilst offering different services - mainly to patients requiring intensive treatment. When interviewed, patients talk about a more positive sense of wellbeing, simply because they have a quicker access to their health data. This confirms the idea that general infrastructures are not the best representation of users. What Greenhalgh *et al.* (2010) have understood from the NHS, become here clearer. Patients consider data something personal, to use personally and to build a composite identity when a sickness incurs. The population should be divided into specific target-groups, to help everyone with specific functionalities (Butler *et al.* 2013). Some users are interested in “simple” services such as fast access to lab tests or general advices on wellbeing. More intensive user are interested in dedicated functions to monitor specific symptoms whilst realizing more effective progress in their diagnosis investigations. Specific design of these infrastructures should be addressed to open connections to players, enabling them to generate tools for auto monitoring or to analyse eligibility to screening programs (Davidson *et al.* 2015).

A final problem is one relevant missing actor in the scene. These infrastructures are putting aside the general practitioners. There is no strategy to share information between their medical programs and this public infrastructure. A sort of alliance has been developed with specialists, as they need fresh data always to set the therapies. It seems nothing like what GPs want to do with this infrastructure. And so far, Governance is still concentrated on specific ‘vertical’ performances (systems requirements) and specialist treatments.

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