



‘Two clicks and I’m in!’ Patients as co-actors in managing health data through a personal health record infrastructure

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Abstract

One of the most significant changes in the healthcare field in the past 10 years has been the large-scale digitalization of patients’ healthcare data, and an increasing emphasis on the importance of patients’ roles in cooperating with healthcare professionals through digital infrastructures. A project carried out in the North of Italy with the aim of creating a personal health record has been evaluated over the course of 5 years by means of mixed method fieldwork. Two years after the infrastructure was put into regular service, the way in which patients are represented in the system and patient practices have been studied using surveys and qualitative interviews. The data show that, first, patients have become co-actors in describing their clinical histories; second, that they have become co-actors in the diagnosis process; and finally, they have become co-actors in the management of time and space as regards their specific state of health.

Keywords

ehealth, electronic health records, health data, health infrastructures, health practices, personal health record

Introduction

In recent years, due to the economic crisis and cutbacks in resources following decades of continuing expansion, it has become increasingly urgent to take action to ensure the sustainability of public health systems, without, however, reducing the expected quality of service.¹ However, the first consequence of these changes is a growing demand for co-responsibility on the part of patients, who must take increasing responsibility for a capacity to pre-empt healthcare issues and manage their treatments independently. The healthcare system has also traditionally responded to these challenges by investing in healthcare infrastructures aimed at improving professional coordination and streamlining workflow. For these reasons, the infrastructures in healthcare have attracted increasing interest from scholars regarding their relevance in ‘connecting practices, change existing practices and create new practices’.^{2–6} More recent developments, however, have focused on infrastructures

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for patients, such as patient portals and personal health records (PHRs). These infrastructures should be able to support the relationship between patients and healthcare systems without losing the quality of service that people expect, while maintaining trust in their contact with healthcare professionals. This requires a special investment in infrastructures that are especially sensitive to the needs of patients, that are designed according to their needs, while at the same time increasingly able to support the relationship between patients and healthcare professionals.³ Recently, infrastructures have moved from a general interest in the health system as a whole, to specific patient needs and pathologies such as diabetes, heart disease and many others. Individuals are quickly becoming the new focus of interest.

The PHR infrastructures are specifically created to furnish patients with access to the documents produced by various health information systems. The intention of national and European governments is that all citizens should soon be able to acquire their data from the network and make it accessible to the doctors treating them in whatever country they may be (Italian Law 17 December 2012, no. 221).¹

As we shall see, research on these infrastructures is particularly suited to understanding how patients deal with such situations. PHR systems enter people's lives, and it is important to determine how patients alter their health practices because of PHRs. The article reconstructs the development of a PHR by an Italian regional health authority and closely observes how the role assigned to citizens/users has changed over time. In the space of a few years, in fact, the rhetoric and practices related to PHR have exhibited varying degrees of the 'shift' and 'drift' as recently observed by Davidson et al.⁴ in the United States. Through analysis of this case study and an extensive monitoring programme conducted with both quantitative and qualitative empirical observation, we show how patients derive notable benefit from innovation, despite the fact that it is not specifically designed for them.

Related work

This work concerns a computerized patient records system centred on patients themselves. A common name for this kind of system is PHR. The PHR was originally defined within the American context and more as a policy project than as a concrete operational one. The basic design was developed with reference to the American healthcare system in the early 2000s. In particular, the Markle Foundation was among the first to define the nature of the instrument. In a report devoted to the American healthcare system of the future, published in 2003, the PHR was defined as 'an internet-based set of tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it'.³⁻⁵ This type of system differs from the better known EHR (electronic health record) because it is constructed with direct consideration of citizens and their needs to access health data. In EHR systems, in fact, it is the medical staff who administer the data on behalf of the patients.

The possibility of extending these experimental projects to the entire population of a larger administrative territory – such as a number of metropolitan cities (e.g. Copenhagen), certain large private players (Google Health, MicrosoftVault or myRecord by Epic) and the English National Health Service (with its HealthSpace project) have done – is more complex and uncertain.^{4,6} Studies that have analysed the UK experience, which is possibly the most ambitious in a Western country (12 billion pounds was the cost after 6 years despite an initial provision of 4 billion), have underlined the superficiality with which the interests of actual groups of patients were treated.⁷ In the English system today, only the repository of the clinical data of English patients known as the summary care record (SCR), which is only available to the health service and which stores over 20 million medical records, is available. The HealthSpace system, which was a PHR conceived to

give access to data available from the SCR, to which personal data could also be added, was finally closed down at the beginning of 2013, and the data were securely deleted (National Archives 2013). In a private context, Google Health, which was also finally shut down in 2013, suffered a similar fate.) These experiences have directed attention to the issue of organizational practices in healthcare. In particular, scholars have highlighted the fact that the design of the infrastructures does not take sufficient account of the user's knowledge and generally undervalues the role of knowledge in organizational practices in innovation processes.^{8–10}

Reflection on organizational practices in sociology rests on a long tradition. Authors such as Goffman,¹¹ Garfinkel,¹² and Bourdieu¹³ propounded the first theoretical frameworks within which to analyse social practices. More recently, the field of organization studies has developed various approaches and given rise to diverse research programmes.^{14–16}

These works have evidenced that materiality and social relations cannot be easily separated; hence, the social practices of the actors become the prime object of study.^{16,17} For this reason, practices may be the most appropriate way to study implementation processes in such complex domains. When developing healthcare systems, established institutional knowledge, the expertise of healthcare staff and patients, and the role played by technology and policy decisions require paradigms which are able to take this complexity into account. As Suchman et al.¹⁶ suggest concerning the study of technological prototypes, constructing new technologies is a 'practice of configuring new alignments between the social and the material that are both localized and able to travel, stable and reconfigurable, intelligibly familiar, and recognizably new' (p. 164). In particular, the authors highlight the presence of two 'shifts' in the realization of prototypes that characterize the practices which surround them. The first 'shift' is from the representation of the artefact by its designers to the design embedded in the artefact itself. The second 'shift' concerns the nature of the users' needs, which must be encoded and included in the artefact. This second 'shift' is particularly evident among early users and helps bring out what may be 'somehow latent, unarticulated or even unrecognized by practitioner themselves'¹⁶ (p. 166).

The case study presented here is additionally interesting since the PHR infrastructure to which this study refers seems to have been a success, even if the initial expectations were disappointing. Approximately 4 years after it was implemented, and with the functionalities for patients reduced to the minimum, it continues to attract end-users, is used by over 10 per cent of the reference population and is showing signs of continuing growth.

Thus, from this point, the article endeavours to set out the following question – if projects centred around patients shift from the original aims, why does it appear that this PHR project is working? More specifically, what are the patient practices that have stimulated the adoption of this system and have resulted in its being so widespread in its reference context?

The setting: a story of a public regional PHR

The PHR infrastructure that we have studied was promoted by the central government in an area of Northern Italy that is not only mostly mountainous but is also characterized by the fact that approximately half the population is urbanized. The infrastructure was developed by a research centre, with the initial enrolment of about 500 experimental patients recruited by word of mouth in 2010. It finally became operational in 2012. Today, the service is part of the information system of the regional health authority and has around 60,000 registered users.

The project, funded by the regional administration, began as early as 2005. From the outset, the research centre commissioned to develop the prototype drew inspiration from existing experiences and pursued a vision of the PHR as entirely open and user-centred. The methodology used to identify requirements and to design the graphic user interface (GUI) was participatory, and for this

purpose, it involved various stakeholders in defining the requirements: users, hospital medical staff and general practitioners, together with patients' associations with the support of an academic team.¹⁸ A project coordination board comprised representatives of the regional administrative authorities, the health authority and the research centre. Although the regional healthcare service offered the opportunity to access data centres, this choice was taken up without any enthusiasm, considering that this project, just as many others, would be closed down sooner or later.

The first mock-ups produced by the research centre had as their 'killer application' online access to laboratory reports and medical examinations produced by any of the regional public health centres, and as a consequence, by hospitals. This option was subsequently extended to cross-viewing between adults and family members. Hence, those authorized can view the data of their partners, people for whom they are caregivers, family members and so on. Furthermore, the initial design also included advanced widgets regarding drug usage, a diary to record health problems, graphical tools and some others.

For political reasons, and to justify the large economic investment, at the end of 2010 the regional authorities instructed the regional health authority to bring the system into service. Thereafter, development of the software was no longer under the direct control of the research centre. It was the health authority which decided how to structure the new system, although it did so on the basis of the research centre's work. As a result, no further investment was made in configurable widgets designed for users. Furthermore, security-related issues meant that the methods for recruiting citizens became more rigid. The system's users would be authenticated by means of a smartcard and reader, which were issued by the regional administration to all users requesting them. Of course, this solution made access more difficult because it involved the installation of the reader by users on their personal computers. A help desk was set up to respond to calls for help and to answer emails regarding technical problems, which were then analysed.

Since that time, other services, such as online payments, virtual prescriptions and other minor services, have been made available. Since the official service opened, people have continued to take up the offer to register with the system, and they have consented to what is a quite demanding level of formalization in order to complete the registration process. The service for access to healthcare data alone now has over 60,000 registrants out of a population of over 500,000.

Methods

Since it began, the project has been monitored by means of quantitative and qualitative studies planned and developed by the author with other colleagues for the entire duration of the trial phase, as well as the first 2 years of operation (2008–2013). This article presents data related to four of these activities in particular: the assessment and monitoring actions carried out between December 2013 and February 2014.

Data was provided by means of:

1. A survey conducted with the CAWI (computer-assisted web interview) method to explore user satisfaction. Respondents are given a questionnaire to compile online which automatically produces the data matrix. The technical support was provided by the Department of Sociology and Social Research of Trento. The web interview addressed 6836 users registered with the system at the end of the first year of operation and who had accessed the system at least three times by 2013. Following the invitation by email, 4743 users (69%) viewed the web questionnaire. Among these, 4269 users (62%) completed the questionnaire (90% of those who clicked on the view link). Most of the questionnaires were completed in the first week after the email (59%, the first 2 days 44%). The subsequent reminders

sent at the beginning of the third and fourth weeks were able to collect an additional 39 per cent of online questionnaires (after the first reminder 1160 questionnaires, about 27%, were returned).

2. An analysis of approximately 500 email messages sent to the system's help desk by patients between January and December 2013 as a sample of the period as a whole. The emails were post-coded according to content and evaluated both quantitatively and qualitatively.
3. Ten semi-structured interviews with institutional and technical actors who were responsible for designing the system and putting it into operation. The interviews with institutional stakeholders and designers of the project explored the artefact's trajectory from the initial conception to entry into service. The goal was to acquire from various viewpoints a clear evolution of the vision and design of the system. The interviews, which lasted almost 1 h, were conducted in the actors' workplaces. They were all recorded and transcribed for analysis.
4. Ten detailed interviews carried out by selecting the 10 most frequent patients/users of the system. The interviews with the users explored the changes brought about by this new way to archive and use data after the system's introduction. The interviews concentrated especially on initial expectations with respect to the system, the degree of satisfaction at the time of the interview and interest in future developments. The interviews had an average duration of about 1 h and were all recorded and transcribed for analysis. The interviews took place in the homes of the interviewees.

The overall approach and the analyses that we carried out followed an open-type constructivist logic, as suggested by Holstein and Gubrium,¹⁹ as well as a 'grounded' logic, since there are not many materials for the evaluation of institutional PHR systems in the literature.⁴ Initially, the research data were analysed following typical procedures for each activity (quantitative or qualitative). They were then presented and discussed in a cross-wise and multi-method manner with the stakeholders responsible for the project. Moreover, the qualitative materials were analysed following approaches with special regard to the study of organizational practices. In particular, following the recommendations of Nicolini,²⁰ we tried to get closer to certain practices enacted by patients in relation to changes in the system. Our analysis also includes grounded theory labelling while reflecting on the part played by the researchers who contributed at each stage of the research. When a consistent pattern was recursively found in the texts transcribed, a label was established. Then going through all the transcribed material we merged coherent labels in knots and then subsequently tried to compare the analysis with further readings of the materials collected.

Findings

Thanks to the composite evaluation plan, it was possible to gain a variegated picture of how the system was regarded by its users. In what follows, we discuss some accounts concerning the four actions considered here: the CAWI survey, the emails sent to the system, the interviews with the institutional respondents and the interviews with the most frequent end-users.

A web survey to determine the users of the system

The survey allows us to compare the system population with the demographic and structural population. The data show a clear division of registrants by gender, and the fact that the white-collar middle class was over-represented, especially at the cost of the working class. This confirms that

literacy and access to the system presuppose that the user has specific skills.^{21–23} Finally, to explore different kinds of users, we used simple variables to divide the registrants on the basis of their access to healthcare facilities (28% for chronic problems, 30% for short-term problems and 40% for general check-ups). With regard to patient expectations associated with the infrastructure, it emerged that at the time of registration, approximately 8 out of 10 individuals registering with the system expected to receive precisely those functionalities that were actually available: that is, the direct visibility of the medical reports recorded in the healthcare service's computer system (79%). A further 18 per cent of registrants expected to have a historical record of their data available, while only 2.5 per cent expected to be able to communicate with medical personnel. Just 0.5 per cent of registrants believed at the time of registration that they would be able to send or enter self-measurements. These two latter expectations are the only ones, among those evaluated, which were not actually made available by the system.

Some key questions in the questionnaire may aid understanding as to the reason for the positive assessments of the system obtained by the survey. To the question 'Do you think that the system has been designed and constructed to fit the user', 87 per cent of respondents replied 'very or quite'. To the question 'Do the services provided meet your needs', 92 per cent of respondents replied 'very or quite'.

With regard to the overall evaluations offered by registrants on the system, there was confirmation that the infrastructure simplified their actions (94% very or quite in agreement) and was more advantageous than traditional channels such as telephone, fax and information counters (96% very or somewhat agree).

Help desk emails

A second evaluation action involved analysis of the content consisting around 500 emails sent by users to the help desk, which were sent to report difficulties regarding access to, and use of the system. The questions mainly fell into categories such as 'access problems' (20%), 'problems with viewing reports' (38%) and 'incorrect data problems' (14%), plus other minor categories. As often happens in these cases, the semantic coverage indicated by users did not always correspond to the category of problems treated in the text message. Around 10 per cent of the messages also expressed explicit appreciation of the system. Besides these communications, the emails comprised various dialogues that also included feedback as well as requests. There were emails harshly critical of the difficult access to the infrastructure, but there were also emails which created further opportunities to develop the relationship between citizens and the health system. The two excerpts that follow, despite reporting some difficulties in access, express a highly active, precise and interlocutory attitude by users:

Unbelievable ... One of the worst systems I've ever seen ... 20 attempts to enter ... every time the same story ... For me, 'username' and 'password' would be enough ... to hell with privacy ... in my opinion you should give a choice ... If someone wants to do a login like on all the websites in the world, more than smart!! And then the possibility of having the mobile service ... on your mobile phone (smartphone) ... Not to mention that before viewing a report you have to open 10 pages to be redirected ... I do not see the point of all this complication ... (E121)

The urine tests performed at the private laboratory Alfa, completed on 1st February, are still not available online, even though the laboratory has confirmed the regular transmission of the report. This delay undermines the efficiency of the information procedure and creates considerable distress, considering the user's need for timely information. I await your reply. (E151)

Users also sent emails to the help desk to suggest various ways to change the system. For example, in the following excerpt, the user urges elimination of paper-based transmission because it is no longer useful, which actually occurred about a year later:

Good morning, because I access the system online, I would ask you not to send the reports of my analyses by ordinary post. Best regards. (E250)

Moreover, some emails stated that the design, as conceived for patients, was incomplete and required further functionalities, as evidenced by the following extract:

It would be appreciated if Print included the Labels and Notes entered by users. Thank you. (E471)

Governance witnesses

The 10 interviews with institutional respondents involved the project stakeholders who sat on the governance board. Among them, interviews were conducted with the director general of the health authority, the head of the regional administration, the head of the research centre, the managers of the information system of the health authority, some chief doctors at major hospitals and so on. The interview materials showed that the system was regarded principally as an experimental opportunity to develop a vision on the implications of a PHR model – which had not yet been integrated into the system of health services provided to citizens, and whose use by the entire population was not considered imminent. Even today, in 2016, in fact, healthcare practitioners are not significantly encouraging people to register on the system, and promotional campaigns have not been particularly incisive in regard to enrolments. However, institutional managers, who were aware of the innovations that the infrastructure entailed, also spoke of the system as one that needed to be developed precisely in order to simplify the lives of citizens/patients:

The first time we considered this infrastructure project was in 2010, and my first impression was that it was a system for involving citizens, for handing them management of certain personal information that has always been very distant from them. Initially, the project was conceived for certain specific categories of individuals: educated and chronic patients, and those with particular needs. It is an extremely useful tool for empowering patients. At that time, most people were not aware of its potential. [...] It was only later that we gradually understood its potential as a platform for gathering together many of the digital services offered by the healthcare system. It was the local government that imposed it on us. (Manager 1, Regional Health Service)

What was my initial feeling when they presented the project to me? My wife comes [from a foreign country], and my first thought was that if something were to happen to me during one of my many trips to that country, with a system like this one, a hospital in this foreign country would be able to have access to my information ... This is one of the reasons why I'm in favour of this infrastructure. (Manager 2, Regional Health Service)

These excerpts confirm the distance between the perception of citizens and that of the stakeholders within the regional health authority. The citizens made specific use of the service, and they understand its value in terms of simplification. In contrast, the managers did not seem greatly committed to supporting the process. This attitude had shifted the system's focus from the citizens' needs to those of the health authority, also in response to national directives on the subject of access to health data.

User interviews

The interviews with patients were conducted in order to determine their reasons for accessing the system and to understand the processes by which they adopted it. Of course, these patients were self-selected in view of their frequent use of the system, which often depended on continuous access to facilities – especially for cardiac problems or cancer. The interviews showed that the PHR service was not considered an ordinary health service, but a privileged channel of access to health services. It was a completely new service, which allowed a ‘direct’ encounter with the healthcare system and created new ways to relate with the organization. The rules of access and the services available regarding personal health data were compared unfavourably to the expectations people usually have when utilizing other common Internet services. The benchmark for its functionality was everyday experience with other online services. The citizens interviewed insisted on the novelty of this data reception channel, which had made their lives easier. Immediacy, browser-based access and the ease of immediately printing reports were the aspects most frequently cited by the patients interviewed. These interviews evidenced a new attitude from patients. Over time, the system had moved closer to patients’ needs, and those in an intense relationship with the health services drew great benefit from it. This generated new practices of data access and use, freeing patients from the materiality of traditional documents and the need to constantly consult healthcare information desks.

For this reason, it is important to move closer to the citizens’ practices of system use. It is difficult to identify those practices that have actually been strengthened by the system and foreseen in the design. However, it is appropriate to explore certain new practices generated by patients, as well as those issues discussed with the interviewer. We limit the zoom-in so as to identify the three most interesting practices.²⁰ These should aid understanding of why the system is gaining a growing amount of appreciation from the population, notwithstanding its limited potential.

Practices of representation of healthcare histories. With the infrastructure in place, the practice of representation of personal healthcare history also belongs to patients. For instance, during an interview at the home of a patient with heart disease, who lived in a remote valley in the region subject to this study, we discovered that a computer had become an official part of the environment, in the centre of the room, and in the middle of the table. The patient can easily show the interviewer his new analyses, which he can finally consult freely as soon as they are ready as if he were in a doctor’s surgery, or even better, as if he ‘were a doctor’:

I have never experienced any problems. My son installed everything and now I check my exams for my heart treatment. I print everything so I can keep them separately and for my check-ups with my cardiologist. In this way, I can do my tests here in town and receive reports from the hospital without having to go there any more to pick them up. At the hospital I go to for my consultations (which is outside the Region), I don’t think they even know I do everything by myself. They don’t have this service! I’m proud of it. Once, I was on holiday and I got all the information with me and the doctors were greatly surprised by it!! They said: ‘At least one of the patients has all the exact information about his pathology!!’ Look how good I am at using the system: two clicks and I’m in, and I keep everything under control! (Flavio)

Diagnosis becomes a patients’ practice as well. After receiving some unusual results from a test, patients can immediately google the Internet, send their test results to their friends and colleagues for advice or directly to the specialist working with the patient on the various aspects of his or her illness:

I'm one of the oldest users of the system. I've also given advice on how it could be improved and they listen to me. As a blood donor, I consult the system very frequently after each donation. The thing that really amazed me is the speed: having your exams immediately. For us donors, exams used to arrive in 4 to 5 days, but occasionally even after 10 to 12 days. Sometimes I go and see how my blood parameters are developing ... but now I look at the system and my labels. It's really convenient! Even if the line isn't working I've saved all my tests! On one occasion, I had a problem with my prostate and I did the PSA exam, the 'total' one, and I saw it had gone up, so I got a prescription for more tests to see the 'free' PSA, and the day after I had the results and everything was OK! I look at my wife's tests in the same way! (Giovanni)

Although communication with doctors is not yet supported by the infrastructure, patients can autonomously communicate their health data to various interested parties in order to verify the data and possible effects. Patients become active, and because information is available to them at an earlier stage, they ask the health service to deal with it or seek further consultations.

Management practices of time and space. Our work on the interviews with those individuals who used the system more frequently illustrated a series of changes in practice, which chronic patients had put to use in order to comply with articulation work. In one particular case, for example, a cancer patient had his partner help him manage the infrastructure. This permitted a new method of interfacing with the cancer unit: for example, his partner was able to manage the tests freely without ethical issues arising, because under Italian law, she could not access the test herself because she was not a relative. The couple, who were in constant contact with a variety of specialists in other areas, forwarded the tests as soon as they received them so that the treatment to be followed could be verified. In addition, because chemotherapy can only be performed where a certain balance of blood components is present, the couple were able to manage every movement of the patient remotely and avoid having to travel to the hospital if the proper treatment conditions were not present. They could check them on their own without going to the hospital, and without consulting a doctor:

It coincided with my husband being diagnosed with a tumour. I wanted to have his exams looked at by whom I wanted and how I wanted without always having to ask ... partly because we weren't married at the time, which meant that as far as the hospital was concerned I couldn't access his medical records. They always gave me the laboratory analysis, but not CAT scans, MRIs and PETs. This system has simplified everything for me: I don't ask anyone for anything and I can see everything immediately, so I have more control over the situation. Previously, you needed a few days and we often went for chemo but had come back home because they discovered while we were there that his transaminase was high. When I'm waiting for exam results, I'll go into the system as much as 20 times a day! This is exactly what I expected when I heard about the system. It's also happened that at first, when I travelled outside the Region, I thought I would find the same technology, but it's not like that. On one occasion, we made a pointless trip because there was no wi-fi at the hospital and I wasn't able to show them the tests in our system! One time, we were going on holiday in the Marche and we stopped at a motorway restaurant so I could go onto internet and see the results of the tests without waiting for them and then leave again. (Maddalena)

Conversely, for the same reasons, the husband of a cancer patient asked for his wife's access to the infrastructure to be blocked because she was checking it so often in order to learn new 'signals' from tests, and she would often try to obtain new consultations and treatments with other specialists. This could destabilize the treatment already under way that in cancer therapies must be completed cycle by cycle to measure the results.

Discussion and conclusion: PHR to enact a co-actor

The infrastructure presented in this article enables us to see closely how patients, during the course of the project ‘entering’ the infrastructure, changed their role and practices in relation to the health data and health professionals. We saw how many changes were made by the system itself over the years, overall reducing the centrality of user needs. Despite this, the patients continued to use the infrastructure, by changing their practices, thanks to the new data provided by the system. We underlined the fact that the changes had developed in terms of three different directions: (1) new possibilities in looking at personal, clinical history; (2) new opportunities in dealing with the diagnostic phase; and (3) new relationships between time and space constraints.

As provided by many other researchers, we have observed severe limitations regarding technological design which involve patients.^{4,7,24} And besides substantial problems of interoperability between databases, we confirm that a lack of interest persists on the part of patients in entering their personal data and doing so continuously.^{21,22,24} Thanks to this system, patients enact what Gherardi²⁵ has called ‘formativeness’. This means looking at ‘how the object of practice is formed and how in its forming the necessary knowledgeability is invented and deployed’ (p. 114). The system, in fact, allows a narrative driven by the patients’ clinical history, which is usually extremely fragmented and dispersed. The infrastructure makes it visible on the basis of computerized design criteria. When a new clinical examination is carried out, patients no longer focus on only one examination, but have the immediate possibility to assemble this new set of clinical knowledge in a sequence that is assured by the filing methods used by the system. This represents an opportunity that was once only available to healthcare personnel.²⁶ Although the infrastructure is anchored to a design guided by the healthcare system, with its existence it ‘liberates’ patients, who invent new practices for managing a new state of independence, thereby becoming co-actors in the management of their diagnosis and treatment.^{27,28} These practices confirm the need to safeguard the autonomy of patients, especially when the care activity is particularly intense. Patients with their local practices question the centre of gravity of treatment from hospital care²⁹ and thus free up new relationships and socio-material arenas.³⁰ This is possible through access to a greater amount of information, but also through the capacity to articulate it in time and space.^{27,28,31} Every infrastructure, including the one examined in this case study, must support the situated knowledge of the subjects, and as suggested by Gherardi¹⁰ and Orlikowski¹⁷ it should permit dialogue with the everyday experience of the subjects.

This study confirms that patients, despite infrastructure design quality, when included in a health infrastructure, become proactive subjects and look at the way in which they face personal needs as both consumers and producers. Their personal clinical challenges are the main impetus to make PHR systems a success story.

We can say that good acceptance of the PHR infrastructure does not depend on the design in itself, but rather on the subjects’ ability to identify new care practices through the functionalities made available to them through the system. When patients have access to their personal data, they can reconfigure their relationship with the healthcare system. This seems to be the main reason for the success of the system observed.

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