

**Personal health data and organizational constraints
in new health infrastructures:
some practices to go through fruitfully**

Alberto Zanutto

University of Trento, Department of Sociology and Social Research,
via Verdi 26, 38122 Trento, alberto.zanutto@unitn.it

Abstract. Increasing strategies to perform new way to keep patient involved in health practices are missing often the point. Infrastructures are not able to intercept real interests of patients through wide open services. Personal health data management require personalization and support for personal health practices. Several strategies include the development of Personal Health Record systems (PHR).

In a itali an trial we explored three main strategies that often show a gap to pass over: practices to verify diagnosis; practices to support and manage therapies; practices to face space and time constraints.

Introduction

National healthcare systems represent one of the most complex political challenges of our times. In recent years, due to the economic crisis and a contraction of resources following decades of continuing expansion, it has become increasingly urgent to intervene to ensure the sustainability of the system without, however, reducing the expected quality of service (European Commission 2014). The complexity of the situation is rendered even more acute by the socio-demographic transformations that will lead to profound changes in western healthcare systems over the next few decades.

One of the stimuli that should help with attainment of these changes is undoubtedly the increasing introduction of computerized infrastructures that have the capacity to support the relationship between patients and health care systems without losing the quality of service that people expect and their trust in their contacts with healthcare professionals. The first consequence of these changes is a progressive 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. This requires a special investment in infrastructures that are especially attentive to the needs of patients, that are designed according to their needs, and that are increasingly able to rebalance the relationship between patients and healthcare professionals. A second result will be the nature of these infrastructures, which must be able to help patients with their health-related obligations wherever they are, and throughout the course of the day.

Many trials many settings

PHRs are probably the most intriguing system designed by health institution to improve new model and new practices for taking any specific responsibility for patients. With very few exceptions, the centre of gravity of the projects always lay within the healthcare systems, and it is only in more recent times that patients have been able to become a part of some of the design processes relating to the infrastructures.

Of course, there has been no lack of criticism of these expectations. Many studies have shown that there a great variety of problems are associated with the introduction of these infrastructures. An excessive prevalence of the medical perspective has often reduced patients' comfort levels and led them to abandon the systems that were designed for them (HealthSpace NHS, GoogleHealth). Some works explored in extended way the constraints that infrastructures deal with their objectives and the patients' point of view (Greenhalgh et al. 2010).

Despite the continual recourse to rhetoric on patient empowerment and co-management of pathologies by patients themselves, the systems often seem to pay little attention to their role (patient empowerment rhetoric). In the structure we analyse here, we will see how in a PHR system developed on the basis of placing the patient at the centre, this element is considerably downgraded when the system is placed in service. Both quantitative and qualitative empirical observation reveals that patients still derive a noteworthy benefit from this innovation, however, so why is it that patients whose opportunities to produce useful information and collaborate with the health service by using infrastructures dedicated to

them have been downsized are still satisfied with the new scenario regulated by these same infrastructures?

Related work

The topic of the development of infrastructures in the healthcare sphere has been being explored in various communities for some time now, but the aspect that has attracted the most attention from scholars from the outset is the doctor-patient relationship as created by these infrastructures (Bansler & Kensing 2010). As far as scholars, especially those who study co-operative labour, are concerned, these issues constitute a continuing challenge. The pioneering works of Berg (1997; 1998) and Carl May (May et al. 2001) were among the first to identify the drift, misunderstandings and difficulties involved in looking at technology as a replacement medium.

One of the pathways with which this work wishes to interact is the one that opened up as the result the development of computerized patient records, and more recently of computerized patient records centred on patients themselves, known as Personal Health Records (PHR). These records have offered an opportunity for reflection on the infrastructures that support clinical work. Over the years, computerized medical records have become one of the points at which the old infrastructures have intertwined with the working practices of healthcare staff. Thanks in part to auditing systems, traditional infrastructures usually record patient flows (admissions to and discharges from hospital classified according to the Diagnosis Related Group - DRG), and allow healthcare.

Furthermore, the production of data in geographically remote contexts means that reflection on what takes place, for example, in patients' homes following the introduction of new Communication Technology information technologies cannot be avoided (Gherardi 2010; Piras e Zanutto 2014; Mol et al. 2010).

The PHR experience is possibly the one that has most clearly highlighted the social construction processes of technologies relating to computerized medical records developed with the idea of placing patients at the centre of the design. The purpose of these systems is to "liberate" patients from coexistence with other parties, and to offer them various levels of independence in the management of self-produced healthcare data; these infrastructures place patients in direct contact with healthcare staff (Østerlund et al. 2011; Bjorn and Østerlund 2014; Nazi 2013).

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 and the first two years of operation (2008-2013). This paper presents data related to one of four activities for the assessment and monitoring actions carried out between December 2013 and February 2014.

Whole data were provided by:

1. a survey conducted with the CAWI (Computer Assisted Web Interview¹) method addressed to 6,836 users registered with the infrastructure at the end of the first year of operation and who had accessed the system at least three times by 2013.
2. an analysis of approximately 500 e-mail messages sent to the system's helpdesk by patients. 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.
4. ten detailed interviews carried out by selecting the ten 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 one hour, and they were all recorded and transcribed for analysis. The interviews took place in the homes of the interviewees.

¹ This mode of carrying out surveys has developed and expanded the CATI (Computer Assisted Telephone Interview) method since the early 2000s. Respondents are given a questionnaire to compile on-line which automatically produces the data matrix. The technical support was provided by the Department of Sociology and Social Research of Trento

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 just findings provided by the most frequent end-users. Other field data are under analysis and further explorations.

iv) 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 by 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 especially a privileged channel of access to health services. It was a completely new service which allowed a 'direct' encounter with the health care 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 utilising other common Internet services. The benchmark for its functioning 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 by 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 constantly to consult healthcare information counters.

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 of the new practices generated by patients and discussed with the interviewer. We limit the zoom-in so as to identify three most interesting practices (Nicolini 2009). These should aid understanding of why the system is gaining a growing amount of appreciation from the population, notwithstanding its limited potential.

1. Practices of representation of healthcare histories.

With the infrastructure in place, this practice also belongs to patients. It can therefore happen that in some remote valley in the region subject of this study, an interview with the patient with heart disease carried out in a living room will show that computers have 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! Look how good I am using the system: two clicks and I'm in, and I keep everything under control!" (Flavio)

2. Diagnosis become 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/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 only in 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.

3. 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 that 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 was 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's 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 many 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 into 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 when she changed her practices for access to healthcare data, she would alter her expectations of being cured as a result of wanting to try consultations and treatments that would destabilize the treatment already under way. Here, admission to hospital necessarily means accepting asymmetries with healthcare personnel. Patients must accept stigmatization as being bound to a network of humans and non-humans with a certain course of treatment.

Conclusion

Conclusion

The new e-health infrastructures permit new roles to be developed for patients and new practices to be constructed for the management of healthcare data. Although there have been a plethora of trials in the sector and massive investments for the purpose, computerized healthcare continues to register a series of failures, prominent among which is United Kingdom NHS HealthSpace project.

In this paper, taking what is an apparently successful case as our starting point, we have sought to identify how patients invent new treatment practices thanks to the new infrastructures. Their new margins for action are limited, however, due to a design management practice in which the interests of the health service prevail, but even given these constraints, patients find that there can be significant margins for establishing independence.

Patients appreciate the new opportunities to become protagonists of a new way of managing healthcare data that makes them freer and more dependent. This paper illustrates how this can happen in the areas of diagnostics and treatment. Although the possibilities are very limited – they include electronic filing, the assignment of codes and the opportunity to read medical reports immediately – patients interpret the system as a new style of relationship, with the hope that it might be the beginning of a new relationship with the healthcare system. The expertise that is so often cited in planning documents remains tied to development work, but it is increasingly opening up towards a type of clinical responsibility that is yet to be explored. While it remains an indirect relationship, the change in perspective that infrastructures such as this offers patients is clear.

References

- Bansler, J. and F. Kensing (2010). Information Infrastructures for Health Care: Connecting Practices Across Institutional and Professional Boundaries. *Computer Supported Cooperative Work (CSCW)*. An International Journal, vol. 19, no. 6, pp. 519–520.
- Berg, M. (1997). On Distribution, Drift and the Electronic Medical Record. Some Tools for a Sociology of the Formal. In *ECSCW '97: Proceedings of the European Conference on Computer Supported Cooperative Work*, Kluwer Academic Publishers, pp. 141–156.
- Berg, M. (1998). Medical work and the computer based patient record: a sociological perspective. *Methods of Information in Medicine*, vol. 38, pp. 294–301.
- Bjørn, P., and C. Østerlund. 2014. “Sociomateriality & Design.” In *Sociomaterial-Design*, 15–44. Springer International Publishing.
- European Commission, *Acting together: a roadmap for sustainable healthcare*, White paper on healthcare systems, Brussels 2014.
- Gherardi, Silvia. 2015. “To Start Practice Theorizing Anew: The Contribution of the Concepts of Agencement and Formativeness.” *Organization*, September, 1-19.
- Greenhalgh, Trisha, Susan Hinder, Katja Stramer, Tanja Bratan, and Jill Russell. 2010. “Adoption, Non-Adoption, and Abandonment of a Personal Electronic Health Record: Case Study of HealthSpace.” *BMJ* 341 (November).
- May, C., L. Gask, T. Atkinson, N. Ellis, F. Mair, and A. Esmail. 2001. “Resisting and Promoting New Technologies in Clinical Practice: The Case of Telepsychiatry.” *Social Science & Medicine* (1982) 52 (12): 1889–1901.
- Mol, A., I. Moser, and J. Pols. 2010. *Care in Practice: On Tinkering in Clinics, Homes and Farms*. Verlag transcript.
- Nazi, Kim M. 2013. “The Personal Health Record Paradox: Health Care Professionals’ Perspectives and the Information Ecology of Personal Health Record Systems in Organizational and Clinical Settings.” *Journal of Medical Internet Research* 15 (4): e70.
- Nicolini, D. 2006. “The Work to Make Telemedicine Work: A Social and Articulative View.” *Social Science & Medicine* (1982) 62 (11): 2754–67.
- Østerlund, C., Finn Kensing, and E. J. Davidson. 2011. “Personal Health Records in the US and Denmark: From Visions to Versions?” *Infrastructures for Healthcare: Global Healthcare*, 13.
- Piras, E.M., A. Zanutto 2014. “One day it will be you who tells us doctors what to do!”. Exploring the "Personal" of PHR in paediatric diabetes management”, *IT & People*, 27(4): 421-439 (2014)