Personal Health Records among Institutions, Medical Records, and Patient Wisdom: A Socio-technical Approach

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Abstract. Personal Health Records (PHRs), patient-controlled information systems, are believed to be a key to transform healthcare. We argue that a single system, no matter how it is designed, is highly unlikely to have the power to reconfigure a whole sectors. PHRs are not merely technical objects that exist on their own but they should be considered as socio-technical arrangements of systems and users situated and adapted to the specific context of use. We argue that the design process should follow an analysis of this context with particular regard to healthcare system and local health institutions, e-health infrastructures and the strategies used by laypeople to manage their health. Our reflections are the result of our experience in a research/innovation project aimed at prototyping and testing a PHR for the whole population of an Italian region.

Keywords: Personal Health Record, institutional context, design, healthcare infrastructures.

1 Introduction

In the last years Personal Health Records (PHRs), patient-controlled information and communication systems [1], are receiving a substantial amount of attention from the medical informatics community, policymakers, employers, designers, and vendors. These actors share the expectation that the whole healthcare system could be reshaped and improved by the rise of a *new patient* empowered through this technology. These expectations are fuelled by future scenarios in which laypeople access their health information in remote places through their smart-phones, record data using health monitoring devices, or find hidden patterns behind a seemingly load of scattered information about their lifestyles [2].

These overtly optimistic perspectives, though, need to be carefully evaluated. Paperless healthcare was considered imminent 30 years ago but it is far from being a reality. Electronic Medical Records (EMRs) have not (yet?) created a seamless web of communication among the healthcare professionals and their efficacy is often disputed. If we raise the issue of the failure of EMRs is to remember that one of its reasons is the lack of relevance of organizational, institutional and political factors in their design. In order to avoid the same pitfalls, we argue that PHRs need to be

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considered as socio-technical arrangements of systems and users, situated and adapted to the context of use, rather than mere technical objects [3,4].

In this paper we present a sociotechnical reflection on PHR design drawing on the experience in a research/innovation project aimed at prototyping and testing TreC, a system aimed at the whole population of an Italian region. The paper starts with a brief literature review about PHRs, pointing at the contradiction between the quest for universal models and the need to root the technology in its specific context. This will help us to argue that, despite the claim of universality, PHR as is described today appears to be rooted in the "local" US healthcare system. Moving from this, we introduce the three relevant dimensions to be explored in order to design a PHR and present the research that guided the prototyping of TreC. The system itself is presented and described in the last section before the final remarks.

2 PHRs between 'Ideal Models' and 'Need for Integration'

PHR is a verbal umbrella rather than a clearly defined concept. Even if this statement sounds harsh, the current debate in the medical informatics community has not provided yet a shared definition of this technology. This, though, could be considered a richness of the debate rather than a limit, given that PHRs are still systems in their infancy. For the sake of our argument we can rely on a broad definition of PHR furnished by the Markle Foundation: a system that enables individuals to "*access, manage and share* their health information" [1, p. 13].

Even if PHR is a young ICT, though, in the last years it has attracted the attention of the scientific community. Searching "Personal Health Records" using Pubmed (http://www.ncbi.nlm.nih.gov/sites/pubmed) returns 114 publications only in the last 2 years. It is beyond the scopes of this paper to present a systematic literature review. Our aim is rather to discuss one of its characteristics, namely the implicit positivistic and techno-centric stance it proposes. Many works, in fact, despite some claims about the need for integration with other systems depict the PHR as it a standalone tool whose success will depend on its intrinsic qualities. This view leads to adopt a prescriptive attitude towards what a PHR should be or which functionalities it must have [5, 6, 7], to think in terms of universal functional requirements for PHR systems [8] to assess PHRs with a value analysis of their functions [9] or on the base of the implementation of 'key features' [10].

The underlying assumption behind these works and the approach in general is that functionalities and features are the keys to a successful implementation. The strict focus on features, functionalities and intrinsic characteristic of the PHR in itself, though, seems to be in conflict with the very nature of a newly born ICT that has to find its role and space in a landscape already populated with other ICTs. To put it with Tang and colleagues, PHR can exist only as a part of a larger "environment in which health information about an individual can flow seamlessly among systems used by authorized health professionals, caregivers, and the patient, when the patient authorizes such sharing"[11, p, 122]. This statement is enlightening because it presents the PHR as a system among systems, used by people (individuals) among other people (health professionals, caregivers). PHRs are to be integrated with other systems and we need to know which kind of information they already provide in order to avoid replicating functionalities. On the other hand, we need to understand what kind of patient-provided information healthcare professionals and institutions are interested and willing to receive.

In this perspective, the “listing of universal features” approach presented above, appears to be unrealistic. Moreover, the key features identified in literature make perfect sense in the US health context but are less relevant in others. This is not surprising, as the most of the research and reflection on PHR is produced in north America. Still, different contexts require different sets of features to put them to use in a context made of laws, technical standards and protocols, working practices and personal needs. All these factors have to be considered before embarking in the design of the system. In other words, PHR is the “new kid in town”, a newcomer that has to adapt to local customs and habits, understanding what others do and which kind of relationships are to be established in order to be accepted (and being successful).

3 TreC Design: Exploring National Healthcare System, Local Institutional Context, Regional E-Health Infrastructural Landscape and Patients’ Wisdom

The design of our system started from considering the several different contexts in which our PHR would work. We identified three relevant levels to explore:

1. national healthcare system policies and the political/administrative local health context;
2. e-health infrastructures and systems already in place in the region;
3. personal health information management in the household.

The analysis of each of these levels guided the design phase. In more detail, it allowed to understand what our system could or could not do, what we could legitimately expect from users and what they expected form the system, with which professional systems it could be integrated and more.

3.1 National Healthcare System and Political/Administrative Health Context

Italy has a predominantly public health system. Most of medical services citizen need are provided for free or at a fixed cost (nearly symbolic, in some cases) both by public institutions or professionals and institutions affiliated with the national healthcare systems. Next to them are the professionals and institutions working in the free market. They provide a relatively small amount of medical services, still there are some specific sectors (e.g. dentistry) in which the private sector is predominant. In terms of ICTs, we are witnessing attempts to integrate systems in use in the public sector at least on a regional scale. Affiliated doctors, like the General Practitioners (GPs) have complete freedom to decide whether and what systems to use and are rarely interested in their integration with other ICTs.

The Italian healthcare system leaves a certain degree of autonomy to the local bodies (the Province, in our case), the main actors able to promote infrastructural innovation in the field. The region in question is a small one (½ million citizens approx.) with a single public health institution (APSS). Moreover, the Province is characterized by a high political stability, the local government has a special autonomy from the national one and the whole region is one among the richest of the country. These characteristics allow to consider this territory a privileged locus of innovation. Traditionally, this is particularly true for those initiatives endorsed or sponsored by the Province itself. With only one public health institution, strongly backed up by the local political authority, it is easier for it to make pressures to the private sector (or to affiliated doctors and institutions) to adopt standards.

3.2 Landscape of the Existing Healthcare Technologies in the Region

As already said above, the strength of a PHR relies on the possibility of allowing a seamless communication with other systems. We mapped the medical systems already in use in the region run by private and public professionals. This led to identify many different EMRs in place used by different professionals and institutions (pharmacist, GP; pediatricians, territorial nurses, hospitals, nursing homes and many more). Not all these systems are interconnected.

We hold several meetings with the professionals that use these to find out if they had any plans to allow interconnection with other systems and to which extent. This approach required some time. Still, it helped to have a clearer picture not only of the actual landscape of the existing systems but also to identify a trend in the process of connecting systems guiding the design in order to have TreC connected with those which emerged as the future obligatory point of passage of health information.

3.3 Personal Health Information Management and Self-care

One of the most decisive aspects of the whole design process was the research carried out among laypeople to explore the daily managing of their health. The assumption was that they are already required by the healthcare system to perform a series of activities (e.g. managing the medical records at home) and that their experience can be helpful in identifying needs and system requirements.

A description of methods and results of these studies is presented elsewhere [12,13]. Here we simply summarize the main results, referring to those publications for details. We identified three paper health records classification strategies, each adopted and changed according to the needs of the moment; it was also discovered that people use to take notes and underline official medical records (e.g. lab test) or even to keep a personally-created health diary of some parameter or symptom. We also discovered the great relevance of the extended family in the management of some borderline situations (e.g. elderly that are not fully self-sufficient).

4 Designing a PHR: Introducing TreC

The analysis of these three levels guided the development of TreC. Understanding that a PHR could not possibly be fully integrated with all the existing healthcare systems, we needed to design TreC in order to connect it to the healthcare infrastructures which could grant the most benefit to citizens. The analysis of the first two levels suggested that the “hospitals system” was the best ally possible as it provides access to the largest sources of medical information available (e.g. the most of lab tests, reports and medical imaging). This choice was reinforced by the fact that locally there is a strong attempt to connect of all the different systems used in the public sector; to a minor degree we also witnessed the attempt to loosely integrate public health infrastructure and systems used by GPs.

The research on personal health information management and self care was taken into account when designing specific features. In particular, this analysis suggested the relevance of customizability of the system and the possibility to share data with relatives as keys to adoption by laypeople.

4.1 TreC as a System among Other Systems (Now and in the Future)

TreC is an ‘Electronic Health Booklet of medical reports’: instrumental examinations and laboratory test results are now available to citizens online from health institutions.

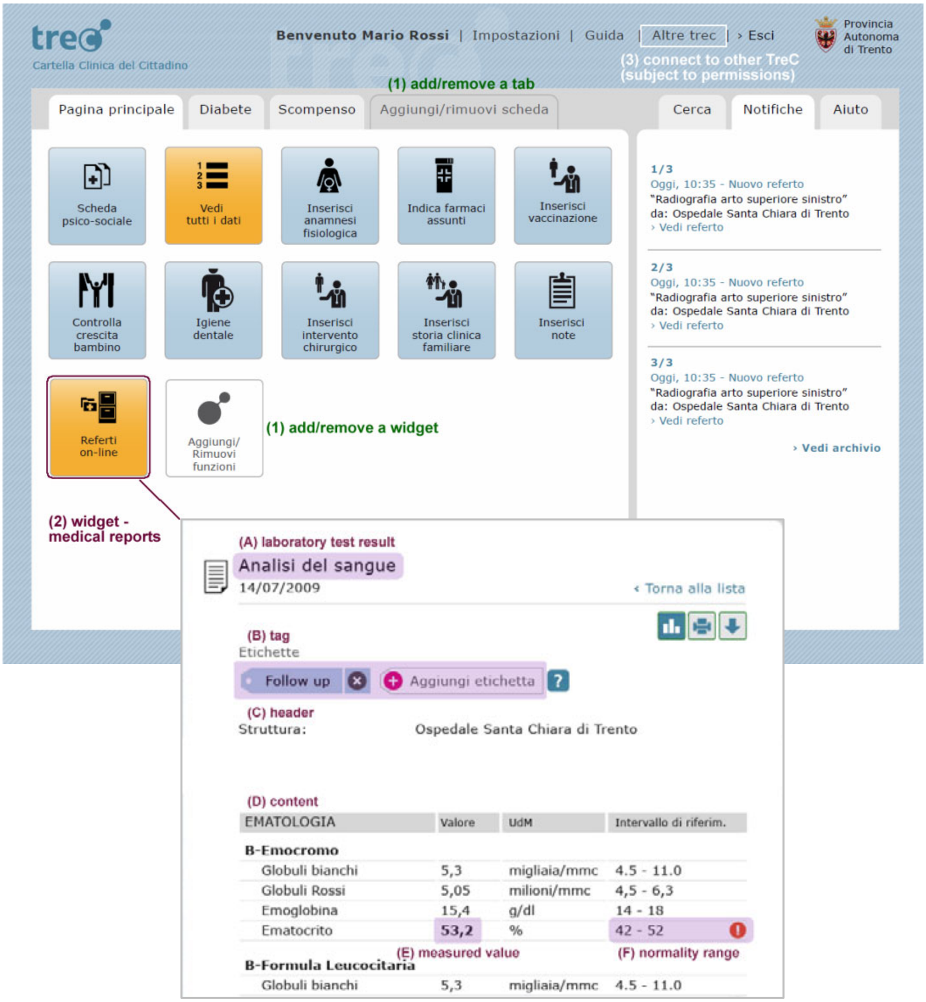
TreC supplements the current Ampere local utility that connect APSS, GPs and pediatrics allowing them to share patient’s health information and personal data. Since Ampere is accessible to patient, the TreC system focuses only on citizens allowing them to collect medical reports, even those not managed by Ampere such as those from hospitals outside the Province of Trento and those from private health care providers. At the moment, citizens can upload images produced by paper-based documents. This file format was chosen so that to guarantee the data trustworthiness.

As regards drug prescription, at present it is only paper-based: prescriptions are written on paper-based special forms by health care professionals and given to patient that has to deliver them to a chemist’s shop in order to have drugs. In this manner prescriptions are documents which “disappear” and do not leave tracks by the patient’s point of view. TreC system is designed to be connected to an e-Prescribing service APSS is working on at the moment. Electronic prescriptions will directly arrive both to TreC and to a chemist’s shop from the point-of-care. In TreC they will be managed as medical reports and be integrated with the patient’s medication history so that to have a complete information on the drugs prescribed to and used.

As for GPs systems , TreC users will not have direct access to those EHR. During an examination, people can give a complete description of their health problems by using information stored in TreC. A patient and his/her GP could also agree on collecting some data at home by using TreC. In this way the GP (with the right permissions) can check the patient’s condition from his/her surgery and decide to get in touch with the patient in case of need. Finally in order to improve communication between patients and GPs an e-mail service with GPs, will be implemented in the TreC, aimed at allowing to ask for an appointment or for medical information.

4.2 TreC as Health Diary

The analysis of personal management of health information revealed the importance to provide laypeople with a space to keep track of data they consider relevant. TreC is, then, a ‘lifeline Health Diary’ where storing personal observations of daily living. This is particularly interesting in case of self-monitoring of patient at home or for healthy people that simply want to check some health parameter important to them. Information such as sleep, diet, exercise, mood and adherence to medication are important to health, but if collected in a clinical setting they are not part of a medical record. In TreC we accept the vision of the Project Health Design [14] that is exploring practical ways to capture and integrate patient-recorded observations of daily living into clinical care, helping laypeople to understand and interpret them. According to it, people are not thought in terms of clinical episode and manage their health on the base of their everyday health needs. In TreC we have extend ProjectHealthDesign's data model so to include information such as family health history or emergency data set given their importance and the fact that only people are able to draw up a list of such data.



1/3
Oggi, 10:35 - Nuovo referto
"Radiografia arto superiore sinistro"
da: Ospedale Santa Chiara di Trento
› Vedi referto

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Oggi, 10:35 - Nuovo referto
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Analisi del sangue
14/07/2009

Struttura: Ospedale Santa Chiara di Trento

EMATOLOGIA	Valore	UdM	Intervallo di riferim.
B-Emocromo			
Globuli bianchi	5,3	migliaia/mmc	4.5 - 11.0
Globuli Rossi	5,05	milioni/mmc	4,5 - 6,3
Emoglobina	15,4	g/dl	14 - 18
Ematocrito	53,2	%	42 - 52 !
B-Formula Leucocitaria			
Globuli bianchi	5,3	migliaia/mmc	4.5 - 11.0

Fig. 1. Screenshots of the TreC. The picture on the top shows an example of a customized home page with several widgets (1), each of which allow to manage specific information (2). The picture on the bottom shows a laboratory test results signed with the tag 'Follow up' (B). The link to other TreC is subject to permissions and it is available on the top of the home page (3).

In order for TreC to be a flexible electronic diary we chose to provide it with simple user applications called “widget”. Each of them offers a few clearly-defined functions (e.g. editing a measurement like weight or blood pressure). By selecting and composing group of widgets each user personalizes the System according to his/her changing needs. The working environment personalization allow relatives to simplify the user interface of an old person with some experience of internet surfing. It allow also to define disease-specific panels to be shared with doctors (Fig. 1.). Regarding data, at any time people can add personal notes and tags to any information in TreC (also medical reports) (Fig. 1.). Tags allow to re-organized data like people do in reality with paper-documents collected in folders. But in TreC this work is simplified since the same data can have more than one tag and so they could be quickly grouped in different way. In accordance to the current Italian law, an authentication procedure prevent the not-authorized access to TreC. Data are not duplicated and are stored in the APSS databases. In this way they are available to people independently from the device in use (e.g. mobile, personal computer or computer at work).

4.3 TreC as an Health Networking Tool for the Family

TreC allow patients to share information not only with their GPs but also with their relatives in order to support the active participation of their families. With regard to the second case, older adults with chronic disease and not fully self-sufficient and parents with babies are individuals that require both a shared management of patient at home and a shared care with physicians.

According to the Italian law, each TreC user is the only owner of his/her personal health information and so he/she states who is allowed to see or manage (part of) his/her data in the TreC System and how long lasts the above consent. Special permissions are provided for parents with underage children and for guardians. Moreover any information in TreC is joined with the person that edited it so that to support the right understanding of the data trustworthiness.

5 Conclusions

Personal Health Record is a promising technology that is considered by many as a key factor to change existing healthcare systems. While this ICT appears promising, though, it should not be forgotten that other “older brothers” such as EMRs have been presented the same way and their results did not meet the expectations. In order to prevent failure and have a chance to be a useful tool in the hand of citizens, PHRs need to be designed in order to fit into the environment they are meant to inhabit. Every health system has features that should be analyzed before starting the design of a PHR. This is especially important for those design processes that aim to build PHRs in contexts outside the United States, and that cannot rely on a literature that proposes reflections and solutions based on a very specific context. In this work we propose to look at three different dimensions before embarking on the design itself: national/local healthcare system and institutional context, regional e-health infrastructural landscape and patients’ wisdom. The analysis of these three levels proved useful in our experience but more research need to be done to identify other possible levels to be investigated in order to have a detailed picture of the complexities PHR systems will encounter in real life settings.

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