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Prescriptions, X-rays and Grocery Lists. Designing a Personal Health Record to Support (The Invisible Work Of) Health Information Management in the Household

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Abstract. For many years the introduction of Electronic Health Records (EHRs) in medical practice has been considered the best way to provide efficient document sharing among different organizational settings. The actual results of these technologies, though, do not seem to have matched expectations. The issue of document sharing has been lately readdressed by proposing the creation of patient-controlled information and communication technologies, Personal Health Records (PHRs), providing laypeople the tools to access, manage and share their health information electronically by connecting to the existing EHRs and other institutional information systems. In this scenario, patients are called to play a major role in coordinating healthcare professionals by providing them the information they need. From a CSCW perspective a PHR offers an interesting case to reflect on cooperative work that requires new infrastructures that intersect organizational settings and extend into domestic environments. So far though, there has not been enough research to shed light on the self-care activities carried out in the households and how these integrate with the organizational practices of doctors and institutions. Our analyses shows that health record keeping is an articulation work necessary for meetings with doctors to proceed smoothly. To do so, people integrate the information contained in medical documents by working on them with annotations, underlinings and integrations. Moreover, we show that health record keeping is a spatialized activity that is inextricably interwoven with the everyday routine and objects. Finally, we provide a tentative classification of three different strategies laypeople use to sort out health records: minimum effort, adaptive, networking.

Keywords: Personal health record, Healthcare infrastructures, Health record management, Invisible work, Self-care, Qualitative research, Electronic health record

1. Introduction. Self-care, personal health records and the evolution of healthcare infrastructures

In recent decades the medical field has undergone numerous changes which have radically altered its overall structure. A particularly interesting example of this

transformation is the change that has taken place in the allocation of health care 34
and management tasks between health personnel and patients. The latter, 35
traditionally relegated to a passive role as the bearers of symptoms to be treated, 36
are more frequently required to become active subjects, especially in processes of 37
self-monitoring and self-care. In parallel, health personnel are required to 38
undertake work to educate and empower patients so that they can independently 39
perform certain activities in support of therapeutic action. 40

This new role performed by the patient depends primarily on the increase in 41
degenerative and chronic diseases that often accompanies a rise in the average 42
age of the population. In this context there arise the conditions whereby greater 43
importance is given to “management and care” than to “treatment and cure” 44
(Gerhardt 1989), thus opening the way for more democratic and participatory 45
forms of illness management (Porter 1997) able to involve patients made 46
increasingly aware and informed also by the traditional media and the Internet 47
(Bury 2001). However, it seems that a decisive contribution to this shift has been 48
made by the growing management costs of healthcare institutions, which seem 49
increasingly concerned to furnish high-tech biomedical care directly, and to 50
delegate the management of routine activities to patients and their relatives when 51
they require just elementary clinical competences. 52

According to a rhetoric shared by policy-makers, health institutions and the 53
manufacturers of widely-used medical technologies, it is precisely the increased 54
involvement of patients that is the key component of a new pact between patients 55
and health institutions that enables the former to safeguard their autonomy (at 56
home/work) and the latter to focus on the acute phases of pathologies (in 57
hospital). New healthcare models envisaged by researchers, technologists and 58
politicians have drawn on these suggestions to conceive a Patient 2.0, a subject 59
able to use smart home-monitoring devices and the internet to access medical 60
information of concern to him/her (e.g. lab tests, x-rays), produce clinical data 61
(e.g. through glucometers, blood pressure monitors), and to be more knowledge- 62
able in interactions with doctors or in his/her own action (e.g. information on 63
medicines and therapies, or medication adjustment). 64

In this context, healthcare infrastructures, usually considered as instruments for 65
professionals and institutions, must be re-thought as tools able to support a 66
polycentric health system in which patients are considered to be producers and 67
managers of health information on a par with doctors, nurses and health 68
organizations. 69

The plausibility of these new scenarios hinges on the assumption, as yet 70
unproven, that patients are willing to assume a more participatory role in the 71
management of their health, to learn how to use new tools, and to commit 72
themselves to doing so constantly. These aspects raise interesting issues for those 73
who undertake the design and implementation of the technological systems 74
necessary to support new forms of work distributed between organizational 75
settings (e.g. hospitals) and domestic ones, between practitioners (doctors) and 76

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patients, and between different forms of expertise (lay and professional). It is likely that medical systems conceived for specific uses in a professional setting are not easily adaptable to domestic contexts in which health management practices inevitably interweave with the management of everyday life. The design of new systems therefore requires specific attention to be paid to the different forms assumed by self-care practices in domestic spaces, and to the various activities with which they intersect.

These are the premises of the present study, which analyses the management of personal medical documentation in patients' homes with a view to designing a Personal Health Record (PHR), an electronic system whereby patients can directly access, manage and share medical documents in electronic format.

This study has been undertaken in the context of a health system¹ in which patients usually keep their medical documents at home, with the responsibility of presenting them to health professionals in the case of medical examinations. Usually absent from the documents kept by the patient are those relative to hospitalization (e.g. clinical records, examinations undergone in hospital). However, copies of these can be requested and obtained relatively rapidly.

Patients therefore keep at home:

- logbooks relative to particular pathologies or situations of concern (e.g. pediatric or pregnancy logbooks, diabetes or oral anticoagulant therapy logbooks) used to monitor or keep track of the clinical histories of specific health conditions;
- documentation produced by health services, such as the results of laboratory analyses, specialist consultancy reports, radiographies (once on film, now on cd-rom), ecographs, CT scans, hospital or A&E discharge letters, public health bureaucracy documents (e.g compulsory vaccination certificates), and others besides.

While the logbooks are 'unique items', copies of the other documents are kept at the facilities which have produced them (e.g. analysis laboratory, hospital), so that it is possible to obtain duplicates in the case of loss. This guarantees the backup of information. At the same time, however, such facilities do not directly exchange information about patients, giving the latter responsibility for managing it and for furnishing it to health professionals.²

The next section briefly surveys the debate on the PHR in medical informatics, showing that it constitutes a component of an already-existing ecology of information and communication technologies (ICTs) in use by doctors and health-care institutions. The following section will discuss the concept of invisible work and the importance of knowledge concerning work not formally recognized in the design of collaborative systems. After describing the methodology, the section presents a case study describing and analysing the ways in which medical documentation is collected, shared and filed in the home. The discussion of the results will concentrate on three aspects: the invisible work on documents required of patients to manage the relationship with doctors; the management of

the documents as a practice that cuts across other domestic activities and its 120
 emotional value for the individual; and a typology of forms of documentation 121
 management. In conclusion, some brief considerations are made concerning the 122
 research process and the study's main findings. 123

**2. PHR and its 'older brothers': an overview on the unfulfilled promises 124
 of information systems in medicine 125**

Medical practice has always been accompanied by a more or less refined activity 126
 of record-keeping. During the last century, with the spread of national health 127
 systems and instrumental diagnostics, it became increasingly necessary to 128
 maintain updated registers so as to support the work of doctors and institutions. 129
 Not surprisingly, therefore, medical bureaucracies came to view ICTs as valuable 130
 tools for their work, as testified by the pioneering schemes for the electronic 131
 management of health information introduced during the 1960s (Dick et al. 132
 1997). The spread of electronic devices for data management came 20 years later 133
 in concomitance with the boom in informatics, and it raised enormous 134
 expectations. The Electronic Health Records (EHRs)—“longitudinal collections 135
 of electronic health information about individual patients and populations” 136
 (Gunter and Terry 2005)—were considered by a wide array of health personnel, 137
 policy-makers, health service managers, and public opinion-makers to be 138
 instruments able substantially to improve every aspect of health-care delivery 139
 while reducing economic and organizational costs. It was believed that the 140
 possibility to share information among diverse healthcare practitioners would 141
 improve inter-organisational coordination, enhance intra-organisational efficiency, 142
 yield higher healthcare quality and fewer errors (Vikkelsø 2005), but also to 143
 reduce complexity and specialisation coordinating work among different contexts 144
 and users (Ellingsen 2003). 145

Unfortunately, as Carsten Østerlund (2008) notes, 146

*[t]oday, despite extensive efforts to develop universal and integrated record 147
 systems, one finds that individual settings, departments, and sub-disciplines 148
 within healthcare facilities have implemented their own information systems. 149
 Emergency departments will typically have one electronic record system, the 150
 Intensive Care Unit (ICU) another, outpatient care a third, and nurses (in 151
 some hospitals) yet another nurse-use-only online record system; rarely do 152
 these systems communicate. (Østerlund 2008: 195-6; emphasis added) 153*

Various studies have shown that this scant integration is due to a superficial 154
 analysis of complexities at organizational level (Winthereik and Vikkelsø 2005; 155
 Hartswood et al. 2003). In fact, the projects for simplification and integration 156
 which healthcare systems have implemented in recent years—for instance 157
 through adoption of EHRs—have invariably revealed the shortcomings of such 158
 representations and the enormous quantity of unwanted effects produced by each 159

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experimental scheme. During the design phase, most evidently responsible for 160
this situation is the excessive trust placed in the standardization of procedures and 161
the scant attention paid to workflows of individuals, together with a failure to 162
assume the user's point of view (Hartswood et al. 2003). At the same time, the 163
fruitful contribution made by Computer Supported Cooperative Work in recent 164
years has highlighted the importance of design dynamics and relations between 165
designers and local users (Ellingsen and Monteiro 2006). 166

The design rhetorics which have accompanied and constructed EHRs have 167
prioritized a mechanical idea of the health organizational system, assuming that 168
its individual components would be able to integrate and coordinate themselves 169
via such instruments with other parts of the health system connected with them. 170
Instead, we have witnessed the growth of an array of systems 'by profession' 171
(one for the nurses, one for the doctors, one for the laboratory technicians) that 172
co-exist in a hospital department and are used more to coordinate action with 173
counterparts in the department than to exchange data with other professionals in 174
the department or externally to it (Østerlund 2008). The latter use information 175
systems closely tailored to specific needs and insofar as they serve to manage the 176
workflow and can even 'boycott' systems which are less specific but would 177
enable communication among practitioners (Bruni 2003). This lack of commu- 178
nication among systems is not due to strictly technological factors; rather, it 179
results from the scant importance given to communication with other more distant 180
actors by the various actors that use such systems. In other words, creating a 181
seamless flow of information is apparently more an exigency of the healthcare 182
sector than of individual health practitioners. 183

More recently, the issue of health information exchange between doctors and 184
the institutions has been reconsidered from a new perspective centred on the 185
patient. More specifically, the patient is considered to be not 'the object described 186
in the documents exchanged among doctors', but rather 'the actor most concerned 187
with the flow of information through the carers' network' so that the best possible 188
treatment is ensured. These instruments, usually called Personal Health Records,³ 189
have attracted the interest of researchers and policy-makers alike. This is 190
particularly true of the USA where, for instance, the Office of the National 191
Coordinator for Health Information Technology has considered the PHR as the 192
main information tool to allow people to have personalized care, one of the four 193
strategic actions for the decade starting in 2004 (Thompson and Brailer 2004).⁴ 194

The first aspect to consider before embarking on any discussion on the PHR is 195
that the debate has never produced a wide consensus on its key features and there 196
is not even a single implementation on such a scale for it to be used as a reference 197
standard (Halamka et al. 2008). Hence the PHR is a linguistic artefact 198
(Czarniawska-Joerges and Bernward 1990) requiring stable definition, rather 199
than being a concrete technology—if the numerous prototypes now being tested 200
are excluded. This linguistic artefact is used in the debates ongoing in the 201
scientific community of medical informatics, and particularly in its branch known 202

as Consumer Health Informatics (Eysenbach 2000). Over time, this community has come up with the following definition:

[A PHR is] an electronic application through which individuals can access, manage and share their health information in a secure and confidential environment. It allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it. (Markle Foundation 2003: 13; emphasis added)

The second aspect to bear in mind is that this linguistic artefact is always presented in these debates as part of a broader network of already existing health information systems, which should furnish it with all the medical information concerning the patient.

We envision an 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. (Tang et al. 2006: 122; emphasis added)⁵

The systems referred to are those already adopted by healthcare institutions, general practitioners, hospitals, and every healthcare setting in which medical information on individuals is collected and stored. The highlighted part of the quotation evidences the underlying reason for interest in the PHR by scholars and policy makers: the conviction that this new technology can help to generate a seamless flow of information, which is the Holy Grail of medical informatics research.

In light of the unfulfilled expectations concerning the information systems used by doctors (EHRs), we shall consider the PHR as a ‘workaround’, a system which circumvents the problem of interconnection among systems by creating an ICT controlled by the individual patient entitled to obtain his/her own medical data. The digital access to health information is the basis for re-designing the electronic infrastructure of the healthcare system, which is enriched with a new artefact acting as the interface among existing medical information systems. From this point of view, the PHR is interesting not as a specific technology *per se* but because of the infrastructural changes that it prefigures.

3. From the invisibility of the personal management of health data to its formalization

Medical informatics seems to propose to patients, not a fully legitimated position as ‘cooperative workers’ of the healthcare system, but rather a role as ‘junction workers’ merely involved in a set of activities that keep information flowing from one medical ICT to another. This conception seemingly repeats the same flaw that has undermined the success of EHRs: scant attention to the work practices of the subjects that the designers? supposed would use them. As emphasised by both

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CSCWs and Science and Technology Studies (STS), in fact, the introduction of new technologies often entails a redistribution of work and a new geography of responsibilities within the network (Akrich 1992). We argue that, analogously to what has happened in the design of an EHR, which requires an understanding of the “everyday fabric of practical reasoning in medical settings” (Hartswood et al. 2003), the design of a PHR able to bring real benefits to patients must necessarily be based on analysis of forms of document management, of the domestic spaces in which it is performed, and of the everyday non-health activities with which it intersects.

The prospects opened by current literature in regard to the PHR appear to warrant substantial optimism arising from the conviction that patients, especially if they suffer from chronic diseases (Denton 2001; Leonard et al. 2008), will automatically appreciate the benefits offered by the technology and will be motivated to use it. Yet only few studies have investigated the real willingness or interest of patients in assuming a more active role in the management of their data (see e.g. Winkelman et al. 2005; Civan et al. 2006). Moreover, notwithstanding the emphasis on the need to integrate the medical and domestic workflows (Tang et al. 2006), even fewer studies have investigated how patients actually manage paper-based health documents in the household (Brennan and Kwiatkowski 2003; Moen and Brennan 2005; Unruh and Pratt 2008). These latter studies are of particular interest because they show that the doctor’s access to the patient’s clinical data still largely depends on their domestic management, which should be regarded “as a type of ‘work’ rather than as a personal health-care behavior” (Moen and Brennan 2005, p. 649). Considering it a type of work opens the way to devising tools and ways to support it.

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A further reason for the interest of these studies is that they have disembedded the background activities carried out in households (Star and Strauss 1999) as articulation work (Strauss 1985) aimed at anticipating unintended contingencies and facing the unexpected, but invisible to rationalized models of work.

The in/visibility of these activities therefore depends on whether or not they are regarded as worthy of attention.⁶ The need to make some portions of action visible may arise under the pressure of exigencies felt by the actors concerned (Bowker 1997) or, as in the case examined here, because of a research choice aimed at unveiling the specific relevance of some concealed activities carried out amidst others. Schmidt and Bannon (1992) have argued that in-depth analysis of the politics and culture of articulation is necessary in order to build tools capable of supporting it. However, as they note, supporting cooperative work arrangements requires an unspecified “number of secondary activities of mediating and controlling these cooperative relationships” (id.: 14). As Lucy Suchman puts it, “at some moment, by some means, the specifics of how people work become crucial to the design of the working systems” (1995: 61). Even if the CSCW literature has provided sufficient evidence that not every invisible activity needs to be represented in system requirements (for a discussion see Star and Strauss

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1999), the making of a brand-new technology requires the designers to have a sufficiently accurate representation of the practices which that technology is intended to support/replace; and this requires the disembedding of background work.

A complex aspect of disembedding background work in our case is that, whereas institutional information management is conducted in accordance with standardized procedures and internal organizational logics, the personal management of health documents depends on situated domestic logics. These personal activities are on the one hand organized to meet the requirements of the health institutions, which entrust this work to the patients (e.g. the junction work to ensure the flow of documents among different systems); on the other, however, they may assume innumerable configurations depending on the personal history (see e.g. subsection 5.4). The work by patients therefore has a hybrid nature because it is conditioned by organizational needs and individual/domestic logics, and it assumes importance in the design of infrastructures. The design process must take account of this hybridization in order to avoid the definitive obscuring of processes that have hitherto enabled the health system to work.

The junction work of keeping one's medical records flowing among the medical ICTs, in fact, does not possess the full visibility of formalized work practices nor the total invisibility of articulation work. It is opaque rather than invisible, and its opacity derives from the fact that it is not carried out as a specific activity but is rather a part of the complex ecology of organizational work determined by the health system's current informatics infrastructures.

As a consequence, supporting this invisible articulation work requires the selection of some of the activities that the system seeks to support, not all of them. Here 'selecting' means rescuing certain activities from obscurity but, at the same time, leaving the rest in the limbo of invisibility.

For these reasons, we need to understand what people do with their medical records in order to understand if the 'sharing function' can be easily disembedded and attributed to a technology that does nothing more than that. At the same time we need to identify the activities involved in the sharing of documents so as to create a system able to maintain balance in an electronic (infrastructural) system which on the one hand comprises some of these 'opaque' activities and, on the other, considers and enhances the activities of subjects able to support them.⁷

4. Focusing on the paperwork. Research design and methods

This study is part of a broader research and innovation project in the field of electronic healthcare ongoing in the Autonomous Province of Trento (north-eastern Italy with around half a million inhabitants). The project is called TreC (*Cartella Clinica del Cittadino—Citizen Clinical Record*⁸) and intends to produce within a 3-year period (2008–2010) an electronic tool for health information management to offer to users of public health services in the Province, which is

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financing the project. The first part of the project, from which this analysis 326
 derives, consists of a set of research activities centred on producing a prototype 327
 application to be subsequently linked with the province's health system 328
 information infrastructures realized through cooperative procedures involving a 329
 group of patients selected for experimentation. 330

Semi-structured interviews were conducted to determine what purposes the 331
 respondents thought could be served by sharing their health documentation with 332
 doctors, and whether they had specific communicative needs. The aim was to 333
 understand if the junction work assigned by the PHR to the user was regarded as 334
 necessary, and in what circumstances. Although we were aware that deployment 335
 of a new system may have unpredictable consequences, our intention was to 336
 understand whether some of the assumptions behind the rhetorical discourses of 337
 the PHR have any basis, and to provide useful feedback to the team developing 338
 the system. 339

4.1. Sample 340

The research was carried out on 32 families selected by means of a theoretical 341
 sampling procedure (Glaser and Strauss 1967) which privileged families 342
 characterized by needs for care providers or by the presence of health problems 343
 requiring a constant relationship with the healthcare system. Specifically, we 344
 investigated the behaviours of: 345

- 16 families with children aged under 14 because, until that age, children are 346
 treated by a paediatrician, i.e. a doctor different from that of their parents; 347
- 16 families without children aged under 14 years but with at least one 348
 member with a chronic pathology and therefore treated both by a general 349
 practitioner and at least one specialist. 350

With few exceptions (see below), the interviews were conducted in the 351
 respondents' homes. When the partner was present, he or she was invited to take 352
 part to the interview. This happened on 10 occasions out of a total of 42 353
 interviews (in three other three cases the partner participated too briefly in the 354
 interview for it to be considered a proper interview). During these interviews each 355
 partner individually answered questions about the management of their health 356
 data, while information about other family members (children or elderly persons) 357
 emerged from an interaction between the two partners. 358

The selection privileged interviewees belonging to the intermediate age group 359
 because they were most involved in the care of children, the chronically ill, and 360
 the elderly (37 of 42 interviewees were aged between 35 and 64 years; 3 361
 interviewees were aged under 34, and only 2 over 65). 362

A final sampling criterion was the choice of respondents familiar with 363
 computers, the purpose being to have interviewees potentially able to use the 364
 system being development. Interviewees with low or nil computer literacy (6 out 365

of 42), belonging to the older age classes, were selected from attendees on a course in basic computer skills for adults.

4.2. Interview outline and setting

Because PHR is an infant technology, and it would have been almost impossible to ask people to imagine a scenario in which they are asked to use it, we chose to focus on the invisible work performed by laypeople to keep their medical information flowing among the network of caregivers, and also to identify the members of that network.

When possible, we conducted interviews in the respondents' homes (29 out of 32, while 3 were administered at the interviewee's place of work). The management of medical documentation takes place in the home, and we wanted to observe the spaces in which it did so. Our aim was also to map spaces and places so to sensitise designers to issues that matter to interviewees with respect to the technology to be built (the PHR) and the home (Baillie and Benyon 2008).

When it was not possible to conduct the interview in the home, we requested the interviewees to bring their medical documents with them. The interviews were conducted with the health documentation, or part of it, to hand: this aided understanding of the criteria used to classify it; during negotiation by telephone of the interview, the respondent was told that we would appreciate being able to consult the documentation (not the medical information contained in it but rather the methods used to file it) and asked not to put the documents in order before the interview.⁹

The semi-structured interviews were conducted in order to prompt the recounting of medical narratives and the domestic history of health documents. These medical narratives—rich descriptions of episodes of illness—enabled the reconstruction from real cases of how a caregiver network is built, what information is communicated within it, and what specific communication needs emerge. In regard to the domestic history of the interviewees' documents, they were asked to describe in detail the movements of one or more records from the moment when they entered the home until their final storage. The aim was to bring out the material/spatial dimension of document management.

In light of the first interviews, the outline was augmented with questions on the presence of self-produced medical documentation (personal health diaries) and on how information from official health documents (e.g. annotations, underlinings) was supplemented.

The interviews lasted an hour on average. They were recorded and transcribed. During the interviews, photographic material was collected in order to document common ways to manage medical documentation and how they interwove with other routine activities.

Analysis of the interviews moved through three phases. The first of them concentrated on description of how health documents are managed, identifying

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the actors involved, the places in the home where this action took place, the 407
moments when it happened, the types of event with which it was connected, the 408
reasons for its structuring according to particular criteria, and whether these 409
criteria changed over time. 410

The second phase consisted in the writing of a report which was discussed with 411
the multidisciplinary project group (computer scientists, biomedical engineers 412
and developers). This enabled the development team to identify the prototype's 413
functional requirements, and the authors to draw up their plan for interpretation of 414
materials collected in the field. 415

The third phase focused on document management as a support for medical 416
work, integration of the information contained in the documents, and the role of 417
space in their management.¹⁰ 418

5. Results 419

The main research results are now presented in four subsections. The first deals 420
with the 'opaque work' needed for meetings with doctors to proceed smoothly. 421
The second subsection shows how people integrate the information contained in 422
medical documents by working on them. The third presents, also with 423
photographic material, the ways in which spaces in the home are used to 424
manage, classify and access medical documentation. The fourth highlights how 425
medical documents have an emotional value for patients that transcends the 426
purely clinical dimension. At the end of each section there is a paragraph named 427
'implication for system design' in which we summarize the suggestion provided 428
to (and discussed with) the design team. In the next subsection, drawing on these 429
findings, we introduce an analytical classification of the different strategies used 430
to sort out and share the health records. 431

5.1. Not too little, not too much: the tacit knowledge of coordination work 432

Our research confirmed the commonplace observation that it is the task of 433
patients to collect health documentation. Given that a crucial functionality of the 434
PHR system when implemented will be access to/download of medical records, 435
we shall not dwell on this aspect here. Rather, we shall focus on what happens to 436
the documents when they become available to patients, and therefore on their 437
domestic management and their sharing with healthcare personnel. 438

It emerged during the research that patients and doctors take it for granted that 439
the former support the work of the latter by furnishing the documentation that 440
they require as efficiently as possible. Even if both doctors and patients agree that 441
keeping an archive of personal medical records is a good patient's duty, patients 442
feel that they are supposed to know something that has never been told them. 443
Moreover, as no one explicitly teaches how to sort out medical records in the 444

right way, any encounter turns into an examination of the patient's ability to support the doctor's work.

You see it from their faces [doctors'] if you're helping them; if you hand them the documents in the right order you have their full attention, otherwise... Well, they don't get mad at you, but you waste a lot of time if the documents are not sorted out in a certain way. (woman, 47)

Like every activity that is taken for granted and whose importance is apparent when it breaks down, this happens when patients do not do enough work in the management of documents or when this work mimics that of the doctors.

There is a minimum amount of work that doctors expect from patients. It consists in patients knowing what documents to take to an appointment, and in the absence of which they may be asked to make a new appointment. Moreover, doctors expect patients to separate the documents relevant to the appointment from the others.

Our paediatrician gives you a bad look if you don't bring her the medical records in order. If no one is waiting—it happens, sometimes—she smiles at our mess and she helps us find what we are looking for. If there are people waiting outside, well, you see that she is pissed off. (man, 43)

If doctors expect at least a minimum level in the management of documents, in rare cases it may happen that patients organize the information so punctiliously that the interaction becomes paradoxically less smooth. An oncological patient, for example, prepared the documents to take to a check-up with the assistance of a relative who worked in the same department. The latter helped her organize the documents into the order in which she knew the doctors would inspect them, highlighting the data that she knew would most interest them. The doctors' annoyance at what they regarded as interference in their professional sphere only subsided when the patient explained that one of their colleagues had organized the documents. The position between the two extremes (disorder, excessive classification) depends closely on the specific doctor/patient relationship and on the knowledge that the latter acquires in regard to the habits or needs of the former.

An indicator of the taken-for-grantedness of this articulation work is that the interviewees do not refer to it as an activity (the work of classifying) but rather as the normal consequence of a personal characteristic (being/not being a meticulous person). Unless a breakdown occurs. A young woman, accused by the doctor of having lost a test which she swore that she had given him, spent some time describing the "work" (she used the word) necessary to keep her archive in line with the doctor's expectations.

If laypeople are expected to take care of their medical records, people who are not able to do it by themselves are supposed to be helped someone, generally a relative. In this case, health records management is a part of the more general

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activities some people are required to carry out to support someone else’s health, 486
 be it a younger child or a older parent. Sometimes these tasks are shared by more 487
 than one relative (e.g. parents for the children). In other cases these activities 488
 require some degree of coordination, as in the case of separated parents or, 489
 typically, when brothers and sisters take turns in ensuring their older parents’ 490
 comfort and support. In these situations people do not only share documents with 491
 their doctors; they also need to keep each other up-to date about symptoms, needs 492
 for prescriptions, and to coordinate a common ‘perspective’ about their parents’ 493
 condition before seeing the doctors. 494

Implication for system design. The introduction of an ICT to ease the exchange 495
 of information among doctor and patient is likely to radically modify the 496
 perception of the activities carried out by the latter, creating a new arena of 497
 visibility for those practices. If these became legitimate working activities they 498
 could also be more formalized and intelligible to both actors. The system would 499
 not merely support the classifying and sharing activities but it might even be a 500
 key in patient sensemaking, providing not only explanation of what is needed by 501
 doctors but also why. 502

Moreover, a PHR could open a promising field of research and application for 503
 informal caregiving activities, especially as a tool for shared support to the 504
 elderly, a problem for a growing number of families. In this frame a PHR would 505
 seem less a junction of a formal healthcare system (to share data produced by an 506
 institution with other professional) and more a node in a small network of 507
 informal caregivers (to help them coordinate their care activities), providing also 508
 new visibility to these hidden/invisible care work. 509

5.2. Beyond accessing, managing and sharing: the invisible work 510
 with and around medical records 511

A second finding of the research is that documents are not unalterable objects in 512
 the hands of the patients but can be used to enrich, contextualize or highlight the 513
 information contained in them. Direct observation identified three significantly 514
 common ways to act on documents: annotate, underline/highlight, and integrate 515
 them. 516

Annotations take the form of hand-written notes on medical documents, and 517
 they usually serve as reminders. It was found, for instance, that respondents were 518
 accustomed to noting on clinical reports the names of medicines (e.g. a pain- 519
 killer) which had proved particularly effective, or they jotted down the symptoms 520
 that they wanted to report to the doctor (e.g. nausea or fever in pregnancy). The 521
 function of annotations varies according to the case. In some circumstances, notes 522
 are made by the patient in order to keep track of an action undertaken but without 523
 a clear idea of the information’s usefulness. In other cases, annotations have the 524

purpose of informing the doctor *ex post* about therapeutic choices made 525
autonomously by the patient 526

*I make some notes as well, to tell the truth, in pencil, on certain supplements 527
that we make during the course of the illness. You can see the pediatrician 528
once. After 5 days the doctor says, 'Okay, he's [the kid] better'. But if in those 529
days I've changed my son's therapy, I mark it down. See here that we've 530
changed antibiotic... and then I add in pencil... so it serves as a reminder of 531
the change, for me and the doctor. (woman, 45) 532*

Sometimes it is the doctor him/herself who suggests keeping track of 533
discontinuous symptoms, and in this case the official medical documents may 534
become the space for recording such information. 535

*This is my handwriting. These are notes that I've made. You see: chickenpox, 536
measles, scarlet fever. Here, here, all marked. I did it then because the 537
pediatrician suggested I should keep track of the problem and the medicines 538
used. (woman, 44) 539*

Underlinings, made with a pen or a highlighter, are often used to make a 540
value immediately visible (e.g. triglycerides in a complete blood test). By 541
underlining, patients undertake work largely intended to attract the doctor's 542
attention to particular information, as in the case of the oncological patient 543
presented above. 544

Integrations consist of matches among 'official' materials, and they signal the 545
belief that the information contained in the medical document is insufficient. In 546
one case, a parent had the habit of clipping the part of a vaccine package bearing 547
the batch number to his son's vaccination certificates, in case the batch later 548
proved to be infected. Other forms of integration consist of placing side by side 549
official health records and other information such as printouts from the internet, 550
often to show them to the doctors. In some cases these unofficial documents may 551
play a major role in the diagnostic path. 552

*Ah you see, this sheet here, this thing downloaded from the internet by my wife, 553
which was then left among the documents. With this we went back to the 554
oculist, who looked at the papers and said, "Ah yes, in fact it could be a 555
Thygeson keratitis". (man, 46) 556*

These interventions on documents are sometimes accompanied by self- 557
produced health diaries. These are documents which patients usually begin to 558
compile without conferring with doctors. Their purpose is to keep check on a 559
parameter (e.g. weight for a diabetic), a disorder (e.g. a chronic cold), or to 560
identify regularities in an undiagnosed ailment (e.g. the food eaten before 561
recurrent headaches). Some of this information is shared with doctors, and some 562
interviewee reported cases in which those data proved to be the key for 563
subsequent diagnostic activities. 564

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Implication for system design. Personal health diaries or notes, underlinings and integrations to official medical records testify to the wide range of activities that people perform with and around health documents. In particular they shed light on the production of health-related information by lay people both to interact with their doctors and for personal interest. As a general consequence, in order to be accepted, a PHR should support these forms of laypeople's opaque work, allowing them to integrate the information provided by health institutions or professional caregivers in ways that make it easy to tell who wrote what.

Our analysis, however, suggests that the information produced by laypeople has different meanings to their doctors. In particular, the narratives we elicited show that most doctors tend to discard as irrelevant the information of health diaries (with some exception) and do not care much about underlinings. On the contrary, doctors (GP especially) seem increasingly interested in the ability of laypeople to find information about a given health condition; some, for instance, give patients with higher computer literacy the task of finding themselves the best specialists or information about rare diseases through the internet. In other words, some information work seems to shift from the doctors' responsibility to the patients' abilities, slowly dwindling into invisibility. We argue that this is a promising field for exploration and a space for collaborative work between patients and doctors. A PHR could, for instance, be the tool used by laypeople to share their findings (a new cure, an experimental centre, a specialist) and by doctors to provide guidance for search activities. In this sense the PHR may become an interface between the medical infrastructures and the 'opaque' customs present in patients' practices in management of their health data. A cooperative design should take careful account of this negotiation so that organizational attitudes and priorities do not definitively 'obscure' this opacity space, which is instead rich and significant in patients' narratives.

5.3. Classification as a spatialized activity: spaces and trajectories of medical records in the households

A common metaphor used to describe a PHR compares it to an information-hub, a single space where every medical record/data is kept. The idea is that providing people with a data repository always accessible via computer/internet enhances their self-awareness and their ability to share documents with caregivers. This conception, however, is gainsaid by the usual practices of health record keeping and management in the household. Conducting the interviews in the respondents' homes allowed us to discover that the archive is only the final destination of records that spend from weeks to years travelling around the house. Like any spatialized activity, the one that we discovered depended on the peculiarity of the spaces of every single home. Nevertheless, we were able to identify at least three spaces commonly used to manage health records.



Figure 1. A 'Crossroad'.

'Crossroads'. It is rare for people to place medical records in a folder or archive 605 immediately. Before they do so, records are generally kept in a highly visible 606 space (by the entrance door, in the kitchen) and mixed with other kind of 607 documents and objects (see Figure 1). Thus placed, all these documents, health 608 related or otherwise, act as reminders of actions to be carried out in the near 609 future. It is quite common to find an x-ray to be shown to the GP side by side 610 with a fine to be paid at the police station or a shopping list. These spaces work as 611 to-do lists made of objects. A medical record can spend a variable amount of time 612 at a crossroads, even some years. Close to a crossroads it is quite common to find 613 a calendar where all the family's appointments, including medical ones, are 614 registered so as to coordinate family activities. 615

Besides being obligatory points of transit, crossroads are also shared spaces 616 accessible to all members of the family. At such crossroads, therefore, 617 information is mixed that pertains not only to different spheres of everyday life 618 but also to different individuals. This mixture of documents and artifacts serves to 619 ensure flexible coordination of domestic activities among the members of the 620 household. 621

'Archives'. Once used, health records are kept in places separate from other 622 documents. These spaces may be drawers, boxes (see Figure 2) or document 623 folders. Not meant to be needed again, records are kept 'just in case' they 624 may prove useful. They become less important and disappear from view. 625 Sometimes, if the home is not large enough people keep only recent records 626 there and take the older ones outside (e.g. to a garage). The degree of 627 organization in archives varies among individuals. Some are meticulous 628 (fastidious even) and keep documents with a rigid chronological ordering, 629

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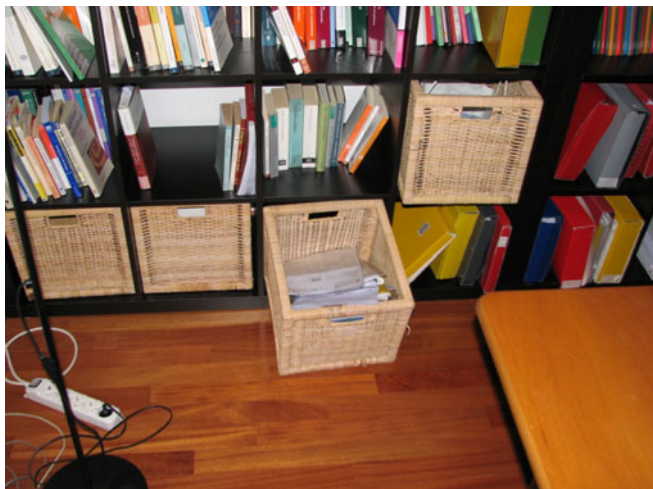


Figure 2. (Archive) A wooden box used as 'temporary archive'.

other subdivide the records by kind (all blood tests, all x-rays). Other, as the 630
 image above shows, simply put records randomly in a given place. If someone 631
 has only few medical records, ordering them has no practical relevance. In 632
 archives, unlike what happens at crossroads, the medical documentation of 633
 each member of the family is kept separately. 634

'Archives-in-use'. People who need or wish to keep a particular health-related 635
 matter under close surveillance generally make use of ready-to-hand medical 636
 records. Often the official records are supplemented by self-created health diaries 637
 and other artefacts needed to monitor or manage the condition; all these objects 638
 are kept together in the space of the house where the managing activities take 639
 place. A woman may keep the 'pregnancy booklet' given her by the 640
 gynaecologist near a thermometer and a personal diary where she keeps track 641
 of the morning sickness, fever and self-prescribed medication. 642

Archives-in-use (and the other artifacts that may accompany them) are highly 643
 personal objects which because of their frequent use become constitutive parts of 644
 daily routine and its rituals, and indeed of personal identity. 645

*I get up and put the coffee on, get out the glucometer, measure the glycaemia, I 646
 go to the bathroom and weigh myself. I come out, I look at the glycaemia 647
 result and the coffee's ready. I pour out the coffee and take a cup up to my wife, 648
 and I've got to write everything: glycaemia, weight, how many kilometres I ran 649
 yesterday. So everything's timed, if I take more time in bathroom, I'm buggered 650
 (laughs). (man, 47) 651*

As in the case of crossroads, also archives-in-use interweave the medical 652
 dimension with the domestic one. At the same time, they furnish a lens through 653

which to observe modes of adaptation to, and management of, certain states of health. Archives-in-use, especially the more complex ones comprising documents and self-measurement instruments, are toolboxes which enable the creation of a seamless web of actions to manage illness and everyday routine (e.g. measuring glucose levels and taking a shower). At the same time, for the researcher, they are excellent indicators of the diagnostic/therapeutic roles that patients attribute to themselves by mixing monitoring actions prescribed by the doctor (e.g. glucose weight) with record-keeping on other parameters that the subject deems important (e.g. physical exercise).

Implication for system design. The spatial analysis of where medical records are located in the house reveals that if a Personal Health Record would have only repository functions, this technology would be used only for those documents that are kept only 'just in case' and not meant to be used much. Medical records, when used, are generally associated to other objects, both other 'official' documents at crossroads (bills, pay slips, a fine to be paid) or self-created diaries and monitoring devices in the archives-in-use (thermometers, pressure monitoring devices). There are at least two implications for system design.

The first is that information is needed where it is needed. If 'highly accessible information' may mean for a computer scientist that it can be retrieved anywhere in the world through a user-friendly designed web portal, for a diabetic it means having such information in the kitchen next to the insulin syringe, not stored in the computer placed in another room. The second implication is that medical data are always part of a highly personal ecology of information and they need to be connected to the rest of it, be it a list of the activities to be carried out during the day or a monitoring device. In their mundane activities, laypersons regard interconnecting these kinds of information as more crucial than sharing every medical record with the network of caregivers. Failing to provide some integration functions may lead to non-use of the technology.

5.4. Emotions within artifacts: medical documents as objects of affection

Some of the records were imbued with particular emotional value. This explains why health-record keeping is, with few exceptions, a personal affair. Unlike other documents, for which a family member acts as the record keeper (the mortgage, the bills), no one attends to health records. As noted above, the special needs of each individual situation induce laypersons to frame the information contained in a document so that it is representative of a unique condition (subsection 5.2).

We witnessed the sincere amazement of many interviewees as they re-discovered among their archives long-forgotten records. Those discoveries brought to their minds episodes, details, bits and pieces of personal life from a forgotten period, fragments of richer narratives useful for understanding the relation between them and the healthcare system. These narratives were elicited

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by the physicality of records, their ordering, the annotations, the post-it notes 694
attached to them, the marks of time and all the other signs that reveal the efforts 695
made to turn cold institutional artifacts into warm personal objects. 696

The most emotionally connoted documents were logbooks. Patients in the 697
Province of Trento have logbooks of various kinds produced by the local public 698
health board, and which can be divided into two categories: those that patients 699
compile personally and show to the specialist doctor during infrequent visits (e.g. 700
the diabetes logbook in which glucose levels are noted), and those in which only 701
the doctor writes but which are kept by the patient (e.g. pediatric and pregnancy 702
logbooks). These objects accompany patients through a significant period in their 703
lives and of which they become an integral part. They are symbols of challenges 704
overcome and efforts made; they testify to diligence or negligence. 705

In some cases, these artifacts were described by interviewees as instruments 706
used for rational purposes. But the descriptions evinced the emotions tied to the 707
fact that those objects ‘spoke’ about their owners. For instance, in the following 708
extracts from interviews with two men, it is not difficult to discern the pride (the 709
first) and the shame (the second) felt at their abilities to manage their diabetes. 710

*I'll show you the values I had before I began exercising. Yes, I was at 157 711
(glucose). Here at 174: I'd eaten too much at a dinner. Here I started running 712
(points to a measurement). I began the preparation. Look: 150, 148, 145, 713
135... (man, 49) 714*

[speaking of some postponed medical appointments] *Lots of times I tell myself: 715
“Well, I won't go to the doctor now. I won't let him see the glycaemia logbook 716
because he's sure to tell me off”. (man, 59) 717*

In other circumstances, although the document did not entirely lose its clinical 718
meaning, it was primarily presented as a cherished object. This happened, for 719
instance, with the pregnancy logbooks (one for each pregnancy). These might be 720
useful to the doctor for the purposes of comparison in the event of a new 721
pregnancy, but they were also kept as reminders of the period when the child was 722
expected. 723

There were finally documents which had entirely lost their original medical 724
meaning and were considered solely as testimonies to a particular period. This 725
was typically the case of paediatric logbooks, which were often carefully 726
preserved so that they could be given to the children when adults. They were 727
affective gifts, therefore, reminders not of clinical history but of parental care, of 728
concerns and sacrifices in the period of upbringing. It was often the arrangement 729
of such objects together with others of a different nature that revealed the new 730
meaning that they had acquired. 731

*What aren't here [among the health documents] are the logbooks. And those I 732
keep, now that I think about it, in a cardboard box together with things from 733
when they were small, for example, the bracelets they put on them when they'd 734*

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just been born [in the hospital]. Things of little importance. They have an affective importance, not a medical one. The baptism candle, you know, that sort of thing. (woman, 41)

6. Implications for system design

The emotional importance of documents raises difficult issues in regard to the design of a Personal Health Record. However, our research is unable to furnish guidance for the system’s development in a specific form. We therefore merely point out the design importance of aspects other than the ‘cold’ management of health information.

The design dilemma can be framed as a choice between allowing or obstructing the emotional connotation of health data. For example, a system could be constructed which deliberately ignores the emotional dimension by proposing an instrument that selects logical clinical data, so that the PHR is a system formally analogous to the EHR managed by healthcare professionals, i.e. a repository of medical information. An alternative approach might be that of allowing connections between electronic documents (or their contents) and digital materials which are not medical but important for sensemaking by patients. In this way, for instance, the weight and height values on a growth chart could be linked to photographs/video clips of the child during birthday parties, and the ‘birth’ event could be linked with the congratulatory messages sent by the parents via email and social networking sites.

This second approach would give users greater freedom by letting them use the PHR as a tool for personal accountability according to individual sensibility. At the same time, however, it should be borne in mind that allowing clinical data to be flanked by bits of personal life would on the one hand make the system more difficult to manage (i.e. with specific authorization procedures for the visualization of information) and, on the other, deprive the system of its healthcare connotation by making it multi-purpose.

7. Discussion. Three strategies of medical record keeping

People do keep medical records. This may sound rather as a naïve way to start the discussion of our findings. Still, we were quite surprised to discover that health documentation is often kept for reasons people were unable to explain. Schein (1984) suggests that a viable rule of thumb to identify the deep assumption of a cultural system is to pose question that make people raise their eyebrows and look at you as if you were mad. We had to face that reaction nearly any time we asked why some of the oldest documents still belonged to their archives. Even those who admitted having been told by their doctors those records were too old to be of any relevance reacted as trashing them would be a mistake. This shows

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that medical records are parts of our self-representation, a proof of something that 773
 have happened to us, a picture we won't be looking again and we are not 774
 completely capable to decipher but still something we could miss if we ever 775
 decided to get rid of it. 776

Anyway, not all the records deserve the same attention in the long run. We 777
 identified three different strategies currently used to sort documents out. People 778
 generally use at least two in their lifetime. Three dimensions of the record are 779
 relevant in the decision of which strategy to adopt to keep it: the perceived 780
 relevance of the information, the foreseen frequency of use and the composition 781
 of the network of caregivers interested in it. These dimensions determine the 782
 classification system adopted and its variability in time. (Table 1) 783

Q4

The *minimum-effort strategy* is the one adopted for the most of the medical 784
 records one possesses. It is aimed at keeping the record with no particular reason 785
 or imaginable future use. If the information the record contains is judged of no 786
 particular interest, if people do not expect to be using the record anymore after 787
 they have shared the record with only one doctor, that record is likely to be kept 788
 somewhere with no particular efforts devoted to its classification. A typical 789
 example of it would be the way people keep their routine blood test their doctors 790
 prescribe them as a preventive measure. If the test results do not require further 791
 exams, the record would be placed in space where it could be eventually retrieved 792
 in the unlikely situation where it would be needed in the future. This space could 793
 be a folder, a drawer or *box* (see Figure 3 above), the fastest way to keep with no 794
 fuss thing are not supposed to be used again. As a general rule, the box is an 795
 archive (see par. 5.2). 796

The use of an *adaptive strategy*, on the contrary, is an indicator of need for 797
 careful attention to a specific condition. This strategy is adopted for those records 798
 that are considered containing relevant information and are supposed to be easily 799
 retrievable for personal consultation and to be shown to a multiplicity of doctors. 800
 These needs require adopting a systematic classification, often devised by trial 801
 and error (see par. 5.1). If the records are about an evolving pathology or if the 802
 network of caregivers changes in time, the classification system may be changed 803
 to adapt to the current situation. One of our interviewee, for instance, had her 804

t1.1 *Table 1.* Three strategies for health record managing at home.

t1.2		Minimum-effort strategy	Adaptive strategies	Shared care strategy
t1.3	Perceived relevance	Minimum or low	High	High
t1.4	Perceived use of	Minimum or low	Frequent	Medium
t1.5	information			
t1.6	Network	One doctor	Oneself plus	A network of formal
t1.7	interested		professional	and informal
t1.8	in record		caregivers	caregivers
t1.9	Classification system	Random or chronological, stable in time	Analytic, flexible	Analytic, stable in time



Figure 3. (Archive-in-use) Artifacts for diabetes management (booklet+blood sugar monitoring device+insulin).

breasts removed due to a cancer. Before any visit she had to go through her huge 805
red folder to select the subsets of her archive needed by her GP, oncologist, and 806
radiologist. As the network grew (i.e. the plastic surgeon) she had to add a new 807
classification system to fit his information needs. An adaptive strategy is 808
generally supported by the creation and care of an archive-in-use (see par 5.2), 809
a given space where specific health records are kept away from the rest. Though, 810
if the problem is resolved and does not require attention anymore, the records of 811
the archive-in-use are moved with the rest of the health records into a general 812
archive. A computer desktop, where files are always visible and constantly 813
modified, deleted, rearranged and placed in new folder could be visual a 814
metaphor for an adaptive strategy in health record keeping. 815

A *shared care strategy*, finally, is the one adopted by one or more people to 816
support someone else like an older relative still able to live on his/her own. In this 817
situation, people are generally helped to deal with some chronic conditions that 818
require often complex medication schemes. Medical records are considered 819
important but, as the situation is stable, are not perceived to be needed frequently. 820
The classification system is devised so to help 'new' doctors (i.e. emergency 821
room) to get a fast grip on the case. What is crucial in a shared care strategy, 822
though, is the higher relevance of laypeople-to-laypeople communication and 823
need for coordination because caregivers need to keep each other up-to-date about 824
the condition of the person they help (see par. 5.1). In light of this, the 825
classification system is also built around their need to support and coordinate 826
their activities. A bulletin board could be the visual metaphor for this strategy, as 827
it recalls both the display of information and the relevance of the informal ones, 828
such as post-its or notes. 829

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These three strategies help us to question the implications of designing a Personal Health Record considering it as merely a tool to help patients to access, manage and share their personal health information. As we discussed earlier, this perspective is aimed both at empowering laypeople giving them control over their records and at making them responsible of synchronizing the whole network of caregivers by giving them access to information.

First of all, as we have seen above, people may need to ‘work’ on each document to add information or underline some; so, a system would require allowing at least the possibility of the user to produce information. To exploit the potential of the world wide web, this should also take the form of allowing users to integrate their PHR with the knowledge sources on the internet (Halamka et al. 2008).

Secondly, sharing medical records is only one of the many activities carried out by laypeople and only the minimum-effort strategy could partially benefit from a PHR aimed just at that. A person with diabetes, a typical adaptive strategy user, would be more interested in an interconnection of all the devices s/he need to manage his/her condition rather than having his glucose level sent to his/her doctor in real time. The sons and daughters of an old couple engaged in a shared care strategy may need to share refill reminders more than the routine lab test of their parents. If a PHR as envisioned by medical informatics proposes the idea of a network of doctors and patients that share ‘official records’, the research shows that real people may have networks made up also of both non-humans (devices) and other people who share ‘personal information’.

This confirms that, as literature suggests, that self-care requires making use of more information than that produced by official medical institutions. Self-care requires a network made of humans (eg. caregivers) and non-humans (eg. measuring devices) which somehow is connected to other technological networks but also to community of peers which provide useful first-hand and lived experience (Halamka et al. 2008). The design of infrastructures aimed at supporting these forms of information sharing needs to be focused on this cooperation activities (Feero et al. 2008).

Q5

We started our research focusing on how laypeople sort health records out in their household considering it as an articulation work to support health professional activities. We realized quite soon, though, that this was not the most interesting issue to address. People use documents in more complicated fashions selecting data inside, adding personal notes or integrating different sources of information. Sometimes, even, creating new health records where to keep track of self-measured parameters or to monitor some conditions in search of diagnostic clues. All these activities are inextricably interweaved as they all revolve around the health records. Moreover, laypeople tend to consider their wellbeing more dependent on other activities than the record sharing with doctors. In this frame, enrolling people as ‘junction workers’ of a new healthcare infrastructure through a PHR does not seem possible unless they are provided

with a system capable to support the multifarious activities needed to support their health. 873 874

A cautionary note is needed, though. Our focus on the particular activities carried out in the household has lead to stress the importance of the coordination work, invisible to the healthcare system. Still, as suggested by Hess and colleagues (2007), at least in the first phase the introduction of PHR system tends to reproduce also the system of expectations and the patterns of doctor-patient communication that existed before implementation of the system itself. In other words, if the design has to be done bearing in mind the relevance of the invisible coordination work of patients, designers cannot forget to support also the visible and explicit work of patients and clinicians. 875 876 877 878 879 880 881 882 883

8. Conclusions 884

The delegation of increasing numbers of healthcare activities to the direct control and responsibility of citizens appears bound to characterize the next decades and to have a significant influence on the planning of healthcare infrastructures. These must be redesigned to take account of the new role of patients, their family members, and other caregivers. 885 886 887 888 889

Teleassistance and telemonitoring projects have been a first phase in which these infrastructures, designed to support information exchange within narrow institutional and professional boundaries, have been extended into people's homes. In these projects, however, the patient seems relegated to a role which in substance replicates the standard logic of the relationship between doctor and patient, giving only limited tasks to the latter (e.g. measuring a parameter and sending it to the doctor). 890 891 892 893 894 895 896

The PHR is a further challenge in this regard because it requires infrastructures to support a technical artifact directly managed by the patient, who is allowed to organize information personally, to produce new information, and to share it selectively within his/her care network. 897 898 899 900

Our analysis, in fact, suggests that support for the personal management of health information, as in the case of the PHR, requires infrastructures able not only to convey information between healthcare institutions and patients but also to enable individual patients to create close-knit, flexible and heterogeneous personal networks. 901 902 903 904 905

Firstly, the everyday practices of health management—typically in the selfcare of the chronically ill—highlight a need to hold different artifacts together and have them communicate with each other. To meet these needs, the infrastructure must enable the patient to construct a personal network comprising, for example, clinical diaries, personal annotations, instruments for the measurement of parameters or for the administration of medicines, and every other object necessary for management of the pathology. In this regard the infrastructure can be represented as a close-knit web of instruments used by the individual patient. 906 907 908 909 910 911 912 913

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Secondly, our fieldwork identified trajectories of illness along which the exigencies of care, support, and document management constantly change according to unpredictable dynamics and in non-standardizable forms. A healthcare infrastructure attentive to these exigencies should be sufficiently flexible to allow the reorganization of care networks to include/exclude new healthcare practitioners or caregivers and to manage the information available according to personal (and changeable) criteria.

Finally, as to be expected, the fieldwork allowed us to observe that domestic practices of health management are inextricably bound up with a series of other personal or family activities, which they condition and by which they are conditioned in their turn. This appears to be the most marked difference between tools designed for the purposes of the health service and health information systems for patients. The latter often manage health information jointly with other information, keeping prescriptions, x-rays and grocery lists together with each other. The management of personal and familial health episodes does not seem separable from the flow of everyday life, and thus combines everyday instruments with those for healthcare. Supporting this heterogeneity appears to be the most complex challenge for the design of new healthcare infrastructures required to handle all everyday activities not strictly connected with health.

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Notes

1. A description of the health system in Italy and in the Province of Trento would obviously be beyond the scope of this study. As an anonymous reviewer suggested, such a description accompanied by comparison “with (e.g.) American or British practice would be very valuable. Indeed, such a comparison would be the basis of a very useful paper in its own right”. We agree with the reviewer and consequently restrict our treatment to the information given in the main text concerning health data management. The central component of Italian healthcare is the public health service, which is universalist and furnishes all medical services at flat-rate costs.

- Paying the same tariffs, patients can choose to use the services of private subcontracting healthcare facilities. 954 955
2. Nothing better than the austere bureaucratic language of an appointment receipt conveys the idea of the patient's role in Italy: "Present yourself with the prescription [issued by the general practitioner], any previous clinical documentation (haematochemical analyses, reports on specialist and/or instrumental examinations) as well as the medicines in use and the provincial health card". This standard formula evinces the salient features of the public health system of the region in question: access to specialist treatment (the main source of clinical documents) requires a prescription issued by a general practitioner; it is conditional on enrolment with the regional public health system (testified by possession of the card); and the patient must furnish the requisite information by taking all previous documentation to the appointment. This requirement is obviously most frequent when a patient's therapeutic needs require treatment by diverse experts, while it diminishes when an illness only requires periodic check-ups with a single doctor. In this latter case, the doctor will have a copy of all that is necessary for management of the patient. 956 957 958 959 960 961 962 963 964 965 966 967 968
 3. We use this label here to denote the technology as it commonly used in the field. However, 'Personally-Controlled Health Record' would be more appropriate because it emphasises the role of the patient's control over the record. The two labels are nevertheless substantially equivalent (Eysenbach 2008). 969 970 971 972
 4. While current debate is dominated by the US it is worth noting that PHR attracted also the early interest European scholars (e.g. Iakovidis 1998) 973 974
 5. This oft-cited article is of great importance because it summarizes the findings of the 2005 Symposium of the American College of Medical Informatics on the development prospects of PHR models. 975 976 977
 6. As rightly pointed out by an anonymous reviewer, all infrastructural work is invisible to those who are not involved in it; hence the administrative work of managing medical documentation in institutional settings is invisible to patients. The latter, however, is considered work in every effect by the healthcare institution, while the domestic paperwork of patients is "personal health-care personal behavior" (Moen and Brennan 2005, p. 649), and is considered such by the patients themselves. 978 979 980 981 982 983
 7. Recent studies on telemedical applications have demonstrated that their use causes unintended and unpredictable forms of work redistribution among not only medical personnel (Cartwright 2000; Mort et al. 2003) but also between doctors and patients (Oudshoorn 2008). We do not expect that this or any other preliminary analysis can foresee what will be the activities to be supported once the system has been implemented and widely adopted. 984 985 986 987 988
 8. The aim of project, as indicated by its name, is to furnish a service to all citizens. In the text, we would have liked to use the expression 'citizen/patient', the purpose being to highlight that this is a universalist service to all citizens. Nevertheless, the design process, as is obvious, has privileged the category of citizens that can derive most benefit from it, namely patients. For this reason, and so as not to encumber the text, we have preferred always to use the term 'patient.' 989 990 991 992 993
 9. During the interviews we were able to verify that the interviewees had not in fact set their medical documents in order. Many of the them reported their surprise at finding medical documents which they thought they had lost or, sometimes, other objects/documents that had ended up by mistake among the medical documentation. In many cases the interview was an occasion for respondents to discard from their files prescriptions never used, examination results become outdated and useless, brochures, newspaper clippings, and even the business cards or telephone numbers of doctors whom they had no intention of contacting again. 994 995 996 997 998 999 1000 1001
 10. A further aspect—the emotional dimension of paper documents—was examined upon suggestion by the anonymous reviewers. 1002 1003

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