User-driven prioritization of features for a prospective InterPersonal Health Record: Perceptions from the Italian context

Federico Cabitza *, Carla Simone, Giorgio De Michelis

Dipartimento di Informatica, Sistemistica e Comunicazione, Università degli Studi di Milano-Bicocca, Viale Sarca 336, 20126 Milano, Italy

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ABSTRACT

In this paper we present two large user studies in which we gather evidence about the adoption and satisfaction level of users in regard to electronic records that manage health related information from two distinct but complementary perspectives: that of General Practitioners (GPs) about their Electronic Medical Records (EMRs); and that of citizens/patients about their Personal Health Records (PHRs). In these user studies we also probe the user attitudes towards innovative functionalities from these two perspectives and, on the basis of the collected perceptions, we apply an original ranking method to infer what features are valued most and hence could inspire design to make PHRs more situated into the users' lives and drive a higher adoption of these tools. On the basis of the perceived shortcomings of current records, we envision an InterPersonal Health Record (IPHR) that is a sort of hybrid electronic record that merges together typical EMR- and PHR-related features and is endowed with specific functionalities aimed at enhancing interpersonal relationships, communication and collaboration between citizens/patients and their GPs *through* the record and *about* its contents. This study is then a contribution in understanding the current attitudes and expectations of potential users towards full-fledged prospective PHRs, as well as a first step in identifying those requirements and priority areas on which to focus further for the design and deployment of more community- and communication-oriented tools in the primary health care domain.

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1. Introduction

Electronic Personal Health Records (PHRs) have become increasingly popular among policy makers [1] and researchers [2]. This lie of the land is mirrored by the growing number of works that use this expression: a simple query on Google Scholar and the PubMed repositories would show clear trends of constant growth of interest in the last twenty years.[1] Although not every of these contributions would adopt the same strict definition of PHR [3], this expression usually (and in this paper) denotes "*an electronic [usually Web-based] application through which individuals can access, manage and share their health information*" [2], not necessarily for initiative of a State or any other Regional body[2]; in

contrast, in this paper we denote with the phrase "Electronic Medical Record" (EMR) the "*electronic [usually desktop] application through which doctors can access, manage and share medical information pertaining to their patients*" (cf. also [4]).

In this paper, we will address the seemingly paradoxical phenomenon why, despite the trends mentioned above, prospective users of PHRs are still oblivious to the potential of these tools or just do not use them: a recent online survey performed by the IDC Health Insights in 2011 found that only about the 7% of the 1199 consumer sample reported to have ever used a PHR; moreover, slightly less than half of these respondents (47.6%), i.e., the overall 3%, were currently using a PHR to manage their family's health [5]. Worse yet, approximately half of the respondents of that study admitted not to know what a PHR was, or that such a thing did exist once they had been informed about its availability. These findings are similar to the results of another survey that the same Institute conducted 5 years earlier showing no significant progress in this regard, both about the actual use of PHRs and the users' awareness of their existence. Another study of 2008 reported that 70% of respondents were not aware of an important nation-wide PHR initiative in Great Britain [6]. In Germany and Austria, a user study found similar levels of general low familiarity

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* Corresponding author. Tel.: +39 02 6448 7888.
  E-mail address: cabitza@disco.unimib.it (F. Cabitza).
  [1] The query was aimed at retrieving all scientific papers containing one of the following phrases "Electronic Personal Health Record", "Personal Health Record" or "Personal Electronic Health Record".
  [2] In this latter case, pundits usually speak of Electronic Health Record (EHR), sometimes giving the same name to both the infrastructure, the platform and the application used by single citizens.

with the concept of the EHR (68% ignored its existence or concept) [7]. One of the two user studies reported in this paper confirms these findings also for Italy.

Thus, what can be behind this phenomenon? Besides themes like "ease of use" and perceptions of "privacy and security" that recur in many literature contributions, the most important factor for PHR adoption and use has been recently shown to be the perceived "relative advantage" [8], i.e., the degree to which a tool (such as a PHR) is perceived as being better than the idea it supersedes; in the PHR case this idea is the transfer of "collect and store" practices of paper based documents into the digital domain. In regard to these practices, the user study mentioned above found that 58% of the German speaking respondents were already used to storing medical documents at home and that in slightly more than a case out of 10 these documents were already in digital format [7]. Our user study found that the practice of storing such documents is much more common and widespread in Northern Italy (96% vs. 58%) and that also a greater amount of those documents is now available in digital format (23% vs. 11%). While these findings could be rightly taken as a precondition facilitating the adoption of the PHR, nevertheless, in light of the concept of "relative advantage" mentioned above, this also requires that PHRs are perceived as something that allows for *more* than just storing and collecting documents, and therefore something that are *something more* than just digital drawers. This corroborates the idea, also expressed in [9] that it is necessary to go beyond the "data container" metaphor, and conceive the PHR as a service that encompasses also the *ability to interact* with others and to embed information in both personal and social practices: in other words, a tool that supports uses in particular contexts for particular social acts that "emerge as a moment-by-moment sequence of talk and action" (cf. Garfinkel) [10]. In the same vein, three studies confirmed that patient-provider messaging is one of the most valued features of PHRs [11–13].

2. Towards an InterPersonal Health Record

The still low adoption of current PHRs, the importance to superseding the "drawer" metaphor and to exhibit a "relative advantage" to their users, as well as the recent findings mentioned above led us to envision a new generation of PHR that could be better be denoted as *Inter*Personal Health Record, or IPHR (see Fig. 1) [14,15].

This kind of PHR adds to the definition mentioned above the crucial capability to support individuals also in "…communicating, collaborating and making sense of their health information, by interacting with the others in order to create both involvement in and commitment on their health". This addition not only recognizes that health is an important part of wellbeing, but also that this latter is inextricably grounded on social relationships and that health data extracted from communication exchanges, i.e., deprived of their context of production and use, would not really reflect a human life, nor possibly affect it. Indeed the prefix of the expression "InterPersonal Health Record" is obviously aimed at stressing the importance for such a tool to be perceived as a means fostering: (i) mutual alignment and continuous communication between individuals involved in the same processes of care and stories of life, i.e., the patients and their caregivers; (ii) the sharing between these people of information, including, from one side, the explicit expression of goals to reach, advices, informed indications and, from the other, expressions of feelings, worries and doubts (beyond the mere sharing of reports, prescriptions and documents); and (iii) commitment and participation beyond technical or procedural interoperability. Since care is a knowledge and information-intensive process, an IPHR is still to allow for the rich
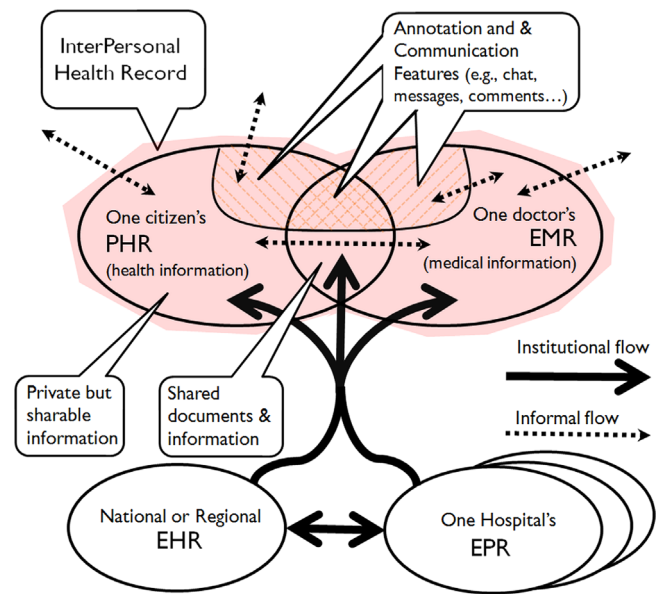

Fig. 1. Schematic model of interaction between electronic records in an IPHR scenario.

management of heterogeneous sets of health data, i.e., it is still a record, not a "social" media. However, recognizing that care is also a collaborative effort (at least between two, the patient and the doctor) calls for an electronic record that supports cooperating actors in both sharing information and understanding each other at a pragmatic level [16] – e.g., not just on what an exam result means, but also on what actions and interventions should be undertaken in light of that result – a goal that could not be reached unless rich interactions between care givers and care receivers occur in the same context of the record, that is aside the health information that must be appropriated to solicit commitment and inform practice.

The diagram depicted in Fig. 1 invites to view an IPHR as a sort of hybrid Web-based application "merging" a PHR and an EMR, where GPs and patients have restricted access to private spaces where not only can they either upload or create content, but also share content (i.e., both documents and conversations) flexibly and informally on either request or need. Conceiving a PHR as something in-between individuals clearly urges to conceive PHRs as applications that not only do supersede the technical integration between EMRs, EHRs and the PHR [17,18] but also egg on the identification and exploitation of functionalities that would help stakeholders collaborate (even in an ad hoc and extempore manner [19]) and communicate (even on an informal and situated level) for sake of sense making and mutual understanding, even if this would require that certain levels of ambiguity, redundancy and incompleteness should be allowed, if not promoted by the system [20].

In this paper we report two user studies aimed at investigating whether both actual and prospective users of a PHR would appreciate the "Inter-" elements outlined above, and whether – or to what extent – they would value the communication- and informality-oriented features of such a management tool, and the extent they would consider its actual integration in their own and situated lives "advantageous" with respect to their habitual practices. In doing so, we aim to address the existing gap "between today's PHRs and what patients say they want and need from this electronic tool for managing their health information [because] until that gap is bridged, it is unlikely that PHRs will be widely adopted" [21].