Trying to Fill the Gap between Persons and Health Records
The MedIcona InterPersonal Health Record

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Abstract: In this paper, we discuss the concept of InterPersonal Heath Record and its role in the most recent models of health service delivery: such a health record should integrate health-related information with communication and collaboration capabilities that could allow both patients and caregivers co-produce information and knowledge toward prevention and illness treatment and management. We then present MedIcona, a full-fledged demonstrator of the IPHR notion developed as free, open-source installation profile of Drupal 7. Its functionalities are aimed at enabling higher levels of user tailoring, content sharing and annotation among patients and their caregivers.

1 MOTIVATIONS AND BACKGROUND

Of all the eHealth applications that in the last 25 years have collected greater hope (and sometimes even hype), the one that has so far fallen shorter of its promises (Pagliari et al., 2007; Westin et al., 2008) is probably the Personal Health Record (Majeed et al., 2009; Singleton et al., 2009; Greenhalgh et al., 2008; Karsh et al., 2010), that is the "Web-based applications through which individuals can access, manage and share their health information" (Tang et al., 2006). This is probably due to many socio-technical factors that would be out to scope to review here extensively (see, e.g., (Heeks et al., 1999; Tang et al., 2006; Greenhalgh et al., 2010)).

Yet, if the success of a technology is to be evaluated also in terms of the adoption rate it has reached where it received sufficient budget and country-wide endorsement, the failure of the PHR is blatant so far. A recent online survey performed by the IDC Health Insights in the US in 2011 found that only the 7% of respondents have ever used a PHR; and slightly less than half of these respondents, i.e., the overall 3%, were currently using one to manage their health (Dunbrack, 2011). Another study of 2008 reported that 70% of respondents were not aware of an important nation wide PHR initiative in UK (Greenhalgh et al., 2008). In Germany and Austria, a user study found similar levels of general low familiarity with the related concept of EHR, as the 68,3% ignored its existence and meaning (Hoerbst et al., 2010). A similar study conducted in 2013 in Italy (Cabitza et al., 2014) reported that only 4 out of 10 respondents claimed to know what a PHR is, despite the fact they were from a great metropolitan area where a Region-wide PHR had existed since the mid-2000s; moreover, whilst for the same Region the National Bureau of Statistics reports that 70 out of 100 used the Internet regularly[1], the aforementioned study showed that only 2 out of 100 used to manage their health documents on line. The same official report shows that while health-related activities are the least performed by Internet users, 81% communicate by exchanging emails, and 51% engage in social interactions with friends and acquaintances in some social media (e.g., Facebook, Twitter, Forums). This grim picture has been recently enriched by the notorious closures or de-facto dismissals of the UK National HealthSpace (Greenhalgh et al., 2010) and Google Health worldwide. Notably, when the creator of the latter system, Adam Bosworth, was questioned on the reasons why Google Health failed, he simply replied: "it's not social!"[2]. On the other hand, it has been also recently reported that 1 out of 7 GPs already uses Social Media to interact with their patients and that 1 out of 3 practitioners would like to use emails to that same aim more often in the next future (Cabitza, 2012).

These reports seem all to convene on the same conclusion that "there is a gap between today's PHRs

[1] http://www.istat.it/it/archivio/78166
[2] http://goo.gl/D8ifl

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and what patients [...] need from this electronic tool for managing their health" (Kahn et al., 2009). That notwithstanding, still a lot of research has to be done to frame and fill this gap, starting from the recognition that the record ought to be considered a component of a complex socio-technical network, that is a communication hub, rather than a mere container of data (Greenhalgh et al., 2010).

Our contribution in this direction is the concept of *InterPersonal Health Record* (IPHR), and the MedIcona system, which is the first instance of this class of applications and its proof-of-concept that can be freely used (and evaluated) by the interested stakeholders. We define an InterPersonal Health Record as a Web-based application where a citizen can store, manage, search, retrieve and visualize personal health data and documents (like her reports, results and certificates) *that is specifically endowed with functionalities aimed at enabling a richer collaboration and communication between her and her (possibly many) caregivers*; this is accomplished by allowing users to *situate* health data in a rich context of interpersonal interactions and, most notably by supporting *co-production*. In MedIcona we reach the first aim by allowing data and at least some of the related social interactions to coexist in the same tasks (e.g., reading some exam results and asking a doctor for clarifications), and some of the representations of these interactions (e.g., their written record) to be tightly linked to the record's data (Day and Gu, 2012). On the other hand, we allow co-production of meaning (Boyle and Harris, 2009) by enabling a tighter communication between the patient and her networks of caregivers and acquaintances so that they can meet in a so called "common information space" (Bannon and Bødker, 1997), that is a place where people collaborate around a central archive of information whose meaning is not simply "given" from one party, or "preexisting" the meeting itself, but it is rather co-constructed in virtue of a shared agreement as to the interpretation and to the pragmatic consequences that are discussed in such space.

In this paper we present a research activity that was aimed at realizing such a concept with open-source and off-the-shelf software as a way to address the research question whether such a communication hub, with its capabilities and the related challenges, is technically feasible and concretely usable.

2 MAKING THE IPHR REAL

In (Cabitza et al., 2013), we made the point that an InterPersonal Health Record must be built on top of the standard capabilities of an electronic record, like secure access, orderly storing, fast retrieval, and then add to these latter ones functionalities aimed at supporting collaboration and communication in a seamless manner, so as to transform the record *also* into a meeting point, as argued above.

As proof of this concept, we designed and developed the MedIcona system, which is to our knowledge the first example of Web application that integrates content and communication to make a record of the former become a means for interpersonal relation and interaction, in short an IPHR. To this aim, we intended communication in a fourfold form, that is in terms of: i) content sharing, in either a 1-to-1 or 1-to-many fashion, also through the notion of "homogenous group of users" (i.e., a circle); ii) content annotation, in terms of either nested threads of side notes, or semantic tags; iii) discussions, which are either topic-related, like in regular Forums, or content-related, i.e., by making each record's resource become the "topic" of a discussion thread; and iv) conversations, that unfold in either an asynchronous or synchronous mode, i.e., like mails and instant messages, respectively.

More precisely, the current implementation of the MedIcona IPHR allows its users to:

1. define customized data templates and instantiate them as forms and charts of the record where to fill in data pertaining their health;
2. upload and tag any external document, to make it a resource of the record and allow for fast indexing and customized retrieval;
3. search and retrieve the record's resources on the basis of keyword- and string-based queries, and get access to contents through two visual timelines that reference all the occurrences of dates that the system finds in the whole record's content;
4. invite anyone with a valid email address to the record as guest, and share with such a guest any individual resource of the record, at various levels of granularity, and for either a limited amount of time or until invite revocation;
5. start a message exchange with guests about any topic in a Forum-like manner, or about any record's resource, in terms of threads attached to the resource itself;
6. collect all messages exchanged with specific users or user categories in one single resource of the record, and send new messages from within the system;
7. undertake instant messaging with guests and caregivers that are logged in the MedIcona system;

8. get access to the most recent information published on the Web regarding the content of specific resources; for patients the system collects resources from certified news sites or patient associations portals; for doctors it lists the most recent papers that have been retrieved from medical databases (like PubMed) on the basis of keywords extracted from the content of the records[3];
9. visualize bar charts or time series on the basis of the data contained in the record (e.g., drug intakes, weight trends).
10. annotate any textual passage, as well as picture, image and diagram contained in the record, and start thread-like discussions on any content and annotations as well.

Before going into the details of this specific IPHR implementation, we need to share a convenient way to represent what an IPHR really is, so that the functionalities mentioned above can look more as a coherent set of factors that enact the twofold (content/communication) nature of the application, than a heterogeneous list of state-of-the-art features.

3 REPRESENTING THE IPHR

Although the definition of IPHR follows from that of PHR in a quite straigtforward way, since the former can be seen as a sort of socially augmented PHR, taking seriously the interpersonal element requires to change the way in which such an application could be offered to their potential users so that they can actually meet with others in the record, and make it a communication hub also. Very simply put then, MedIcona is an electronic record containing resources that can be shared; to represent shared resources these can be represented as nodes of graphs where ownership and visibility are represented as arcs between resources and user nodes (i.e., empty and filled circles in Figure 1, respectively). This metaphor can help us presenting the business models that we invision as consistent with the idea of IPHR. In this paper we outline three scenarios of adoption:

Scenario 1: First the Doctor, then her Patients
– In this scenario MedIcona is given to single practitioners and selected specialists, e.g., for the initiative of either a Regional Health Authority or a pharmaceutical company. These could be partly driven by promotional motives, but also by the potential lying in the anonymous mining and profiling of the practitioners' patients. The specialist adopts MedIcona as her Electronic Medical Record, i.e., an application by which to manage the medical records of all her patients; to this aim, she partly uses the predefined content types, and partly extends them by building the charts, templates and forms that she needs in her profession (more on this ability in Section 4.1). Moreover, the specialist offers MedIcona to each of her patients to share documents (orders, prescriptions, certificates) that she produced and also as a direct communication line with her office. The doctor's EMR and the patient PHR hold resources in common, but they also have private spaces containing resources that are not shared. In other words, MedIcona creates a personal health record for each invited patient (unless this has got already one), who can use it as her own Personal Health Record.

Scenario 2: First the Patient, then her Guests
– In this scenario MedIcona is autonomously adopted by a single citizen/patient (the P red circle at the bottom of Figure 1), who makes it a highly tailored and flexible Personal Health Record where to store her medical documents and other health-related resources (empty circles in Figure 1). Instead of using emails, the patient can use MedIcona also to share selected portions of her record (typically documents, reports and results) with some of her caregivers (e.g., the D green circle on the left in Figure 1), whom she invites through MedIcona itself. These caregivers can get access to the patient's record as guests by logging in MedIcona and, if they like, they can also use MedIcona to communicate with the patient, as well as to store private patient-related data in the same system. Yet, some of these caregivers could use MedIcona as their EMR: in this case, MedIcona asks them whether to create a medical record at her facility for that patient or not.

Scenario 3: Facilities First, then their Clients
– In this scenario MedIcona is adopted by a multi-specialty center or hospital (the H layer in Figure 1): on one hand, the center offers MedIcona to each of its customers, as their free and confidential Personal Health Record (unless they have already got one); this facility record also encompasses several "private" spaces acting as multi-user mono-department Electronic Patient Record, which are used by all the caregivers (doctors and nurses, D and N blue circles in Figure 1) of a department of the facility where the patient has once been admitted. On the other

[3]This service is provided by the Diogene system that NewGo developed also according to our domain analysis. http://www.new-go.it/?q=node/35

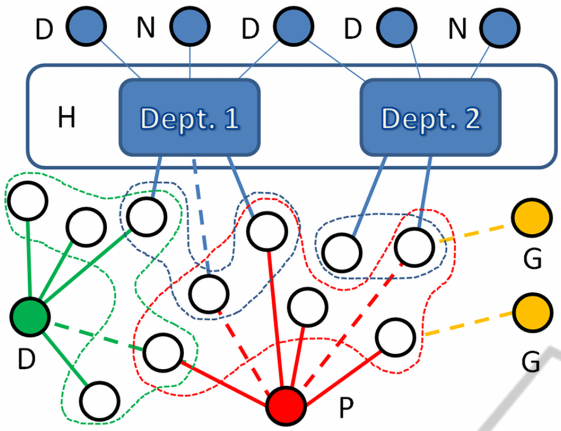

Figure 1: All the 3 IPHR scenarios as a graph.

hand, each doctor of the facility can become a user of a specific MedIcona record, because invited by either the patient or by other doctors of the departments where the patient was admitted; invited doctors (G yellow circles in Figure 1) can get into MedIcona, work with shared resources as well as maintain a private space, which "lives" beside the department private space and the patient private space within the patient record.

Scenario 1 and 2 are symmetrical, while Scenario 3 is more complex only apparently and exploits the modular nature of an IPHR, which essentially emerges from the intersection of multiple private spaces (dotted closed lines in Figure 1) in a number of 1-to-1 common information spaces (the intersections of these areas in Figure 1). As said above, each resource is owned by only one user (continuous segments in Figure 1), i.e., the owner, who can make it visible also to other users (dotted segments in Figure 1), possibly to many (more details on the MedIcona user profiles are provided in Section 4.3).

The current version of MedIcona already supports scenarios no. 1 and 2, but small interventions would make it ready also for the third scenario of adoption. In short, all these scenarios can coexist and reinforce each other, so as to increase the odds to spread the use of such a record among practitioners and patients.

4 CONSTRUCTING THE MedIcona IPHR

In this section we provide some details on the demonstrator we built as proof of the IPHR concept, that we called MedIcona. This application is built on top of Drupal (v. 7), a free and open-source content management system that has been chosen for its diffusion, maturity, modularity and extendability.

Technically speaking, MedIcona is currently a Drupal distribution, i.e., a specific version of the Drupal core packaged with a set of contributed modules, libraries and themes, which are pre-configured in a specific set of default settings. Therefore, the current implementation of the MedIcona system is an interesting case of deep tailorization of a widespread Off-The-Shelf Software to integrate articulated content management policies with social media functionalities. To report on this tailorization task, in what follows we will outline the main implementation choices that characterize the current version.

4.1 Implementing the Record

Before looking under the MedIcona hood, we provide a succinct summary of how users see the "record", that is of the GUI of this IPHR. As said above, MedIcona adopts the record metaphor quite literally. This means that contents are provided in a folder-like page, that is divided in binders and sheets; each binder (or group of sheets) is accessible through a tab and contains either one sheet/resource, or an index, that is a list of resources; the index can be either itemized in a specific sheet or presented as a second-level list of tabs, i.e., a binder. Each resource is displayed in a single sheet of the record. Currently MedIcona conceives the record as a composite artifact composed of these groups of sheets: Forms, External Documents, Images, Conversations, Discussions, Web resources, and the Timelines. The flexibility of Drupal allows to organize the content also differently, e.g., under different tabs, by simply defining new *Views*. These allow the system administrator to define sort of custom high level queries, which can filter contents to be shown to the users, as well as aggregate and present contents in different formats and graphical arrangements dynamically.

The flexibility of MedIcona is also evident in the creation of new content types, i.e., the data structures where users can fill in new data at need, like forms, pages and charts, which are usually displayed under the Forms tab.

4.2 Implementing the Sharing

Resource sharing is the core function by which interpersonal interaction takes place. This is because in designing MedIcona we tried to avoid the idea that the record was the aggregation of static documents and data, and the communication-oriented functionalities were beside this composite set, as sort of juxtaposed add-ons. All the contrary, we conceive any piece of information as a potential trigger for comments and

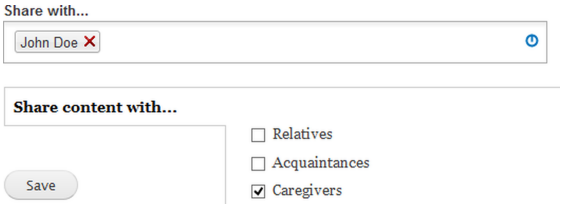

Figure 2: The form to set sharing options for a resource (from the patient's perspective).

discussions: this implies that any record's item must be shared and annotated; on the other hand, we also conceive any piece of conversation or comments as highly informative per se: this requires that any of these items must be searchable and annotable as any other more structured content of the record.

This approach is reflected by the fact that each resource is presented in a page where users find the control to share it to one or more existing users/guests, as well as to anyone with a working email address (see this block in Figure 2). Thus, users can share a content (e.g., a form or a document), the associated comments and annotations, an intervention related to a topic (listed under the Discussions tab) and also a message sent to other users (listed under the Conversations tab). Users can share resources to either single users, or to two or more users. To facilitate this latter case, we also implemented the notion of "circle", which (quite similarly to the Google's notion) represents a predefined set of users that have been previously invited to join the "record" (once again, seen as a meeting place, not just a passive repository of data). In Figure 2 the sharing box is depicted, by which contents can be shared: either by specifying each user with the topmost control, or to all the users that are members of one or more circles.

Implementing resource sharing required to integrate the features of a number of modules. First, circles exploit the features of the *User Relationships* module, which we customized to meet our needs. Then, resource sharing required us to conceive an effective management of resource visibility among users. To this aim, we exploited the features of three modules that we configured to manage possibly joint sets of access control policies, i.e., the *Taxonomy Access Control* module, the *Content Access* module and the access control sub-module provided by the User Relationships module. In this way, MedIcona filters resources by making them available only to specific users or to those users that pertains to the selected circles.

4.3 Implementing user Types

This brings us to speak of how MedIcona users can invite external people to become their record's members, so to say, and how each guest can be categorized. To make this process straightforward, the owners of the record (i.e., patients and single doctors, according to the Scenario 1 and 2 mentioned in Section 3) can invite external users when they share a resource (filling in a new email address). The system catches the request and prompts the user to specify in which circle the new guest should be included.

Currently MedIcona adopts a user structure as shown in Figure 3. According to scenario 1 and 2, there are two types of record owner: i.e., the practitioner that holds MedIcona as her EMR application; and the patient, who holds it as her PHR (refer to Section 3 to distinguish these two cases, which nevertheless can coexist within a single instance of MedIcona). Practitioners and patients can invite a third kind of users, i.e. guests. The Guests role is then further articulated in terms of homogeneous groups through the above mentioned concept of circle (pattern areas in Figure 3) so as to allow record owners to share their contents with a granularity that ranges from the single user, up to a restricted set of users, i.e., one or more circles.

In fact, doctors can invite people also in the "patients" circle; when one of these accepts, MedIcona associates this member with the patient role, that is a special role for which it also creates a specific record that does not expire and that contains private empty forms and binders, as well as the resources shared by the doctor. Doctors can also invite people putting them in other circles (e.g., the colleagues one in Figure 3) and selecting specific resources (or sets of them, up to whole records and sets of records) to be made visible to those guests. In doing so, MedIcona associates those people with the (possibly) temporary role of Guest, whose "record" is populated only with the resources actually shared in an anonymized form, in order to allow the practitioner ask for second-

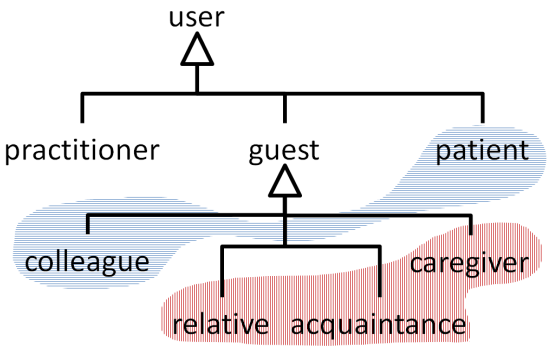

Figure 3: Types of users in MedIcona.

opinion consultation or prime an idea exchange with some specialist.

Patients, in their turn, can invite external guests too, also in this case by specifying what parts of their record they want to share (possibly even the whole of it), for how long and what circle is most suitable to include the guest. To help patients to share resources consistently with both their high concern with privacy and, at the same time, the will for an increasing degree of participation, MedIcona allows them to distinguish between relatives (no time limits), acquaintances and other caregivers (time limited).

We implemented invitations of guest users exploiting the features of the *Invite* module and we configured it to work together with the User Relationships module, in order to allow users to automatically assign their own guests to the desired circles. Circles are defined by the system administrator, who can add or delete them at need: for instance, with reference to Scenario 3 in Section 3, doctors could also see circles for the colleagues of their same department, for those of the same hospital, or of different specialties, and the like. Quite similarly to the content type case (see above), record owners with special rights (e.g., the doctor in the Scenario 1) can define new circles, through the functions of the User Relationships module that are exposed in the "Configuration" section of the Administration panel.

4.4 Implementing Exchanges

Once record owners, i.e., practitioners and patients, have shared something with each other and external guests, they can annotate and communicate about those resources. In what follows we focus on Discussions and Conversations.

Discussions are threads of comments. We distinguish between content-related discussions and topic-related discussions. The former ones are kept as close as possible to the resource that users intend to discuss about. For instance, a patient could need some clarification on a prescription (that is a resource that the doctor has shared with her earlier): to this aim she adds a comment just below the resource in the same sheet. Any response is appended to the list of existing comments for that resource. If the respondent has selected the "reply" command, MedIcona displays the response indented so as to convey the idea that that comment explicitly addresses the former comment. Further comments attached in this way are progressively nested under the root comment, so that the idea of related message exchange is conveyed visually. Nevertheless, users can also attach new comments that are not intended as "replies" to other comments: these will be aligned to the left margin of the page.

Topic-related discussions are treated differently, as they are collected under the Discussion tab (see Section 4.1). In this case, the record owner creates a new resource, namely a topic, and shares it to any of her guests as a way to ask for help, pieces of advice or just an opinion. To this aim, MedIcona creates a sort of small Forum, where all topics are listed in the Discussions page and, once the user has entered the sheet associated with a specific topic, the related responses are collected under the topic, in a similar manner as described above.

Conversation is the concept that, in MedIcona, gathers related threads of messages together according to the correspondents involved, rather than to the "topic" the messages are about (like in the case of discussions). This is because the record owners would want to undertake a written exchange with someone also regardless a specific topic, much alike they would do when they want to write an SMS, or an email or an instant message. The point is that they would want to use an IPHR whenever this message regards their health, or alternatively, is sent from their family doctor (in case of a patient) or from some of their patients (in case of practitioners).

Thus under the Conversations tab record owners can find both a sort of address book, showing the list of all the people that a record owner has invited so far (including the practitioner, if she is an invited patient of hers - see Scenario 1 in Section 3) and, close to each name, the time of the last message exchanged with that person. By clicking on a guest's name, the related conversation sheet is shown: this is possibly empty if no conversation has occurred that far with that person, because only static resources were shared with her. In this sheet, if the selected person is currently an active guest of the record, MedIcona gives the capability to write a message and then share (i.e., send) it to that person: in so doing, the system stores the message in the conversation thread on top of the previous messages. If the person is online at that time, the message will be also displayed in a "chat box" that is placed in the bottom-right corner of each MedIcona page. Otherwise, the message will be dispatched to the email address associated with the correspondent. Also every message sent to online guests through the "chat box" will be timestamped and reported in the related conversation sheet, where no real difference is represented between asynchronous and synchronous messages.

Thus a conversation sheet encompasses the entire history of messages exchanged with that person, i.e., both instant messages and emails, from the most recent on top, to the oldest at the bottom. Notably, if the correspondent is either a practitioner (role practi-

tioner) or a caregiver (role guest in the caregiver circle) for a patient user, or if she is a patient (role patient) for a practitioner user (see Scenarios 1 and 2 in Section 3), by default MedIcona also connects to the mail server of the record owner and downloads all the messages that it finds exchanged between her and the correspondent also outside of MedIcona, i.e., with a regular email client; in so doing, all the messages from and to that person can be found in the Conversations tab, chronologically ordered, and relatively close to other health-related resources, in the obvious assumption that health would be the main talking point with those professionals. Nevertheless, this feature can be disabled, if the record owner wants to collect in the record only those messages that she created and sent with MedIcona.

In order to implement conversations in MedIcona, we exploited the features of the *Drupal Chat* module, and we developed our messaging custom module, i.e., the *MediMail* module.

5 FINAL REMARKS

In this paper we have presented the main aspects of the concept of InterPersonal Health Record (IPHR), which we submit as a step forward to improve the inclusion of Personal Health Records in the daily life of citizens and patients. We started from the recognition that PHRs are nowadays still seldom adopted, if not completely neglected by their potential users, although many enabling technologies are mature and widespread by now, like the recent success of social media and the timeless appeal of electronic mailing show.

We argued that IPHRs can support recent trends and proposals in healthcare service delivery, like coproduction, patient empowerment, patient-centered care, preventive care and self-management, more natively and hence effectively than hybrid solutions that would keep the health documentation of a person *decoupled* from the social interactions and exchanges that she would undertake to make sense of it and make it more *situated* in her own life.

We are aware that this argument can not be validated in a traditional way, as the diffusion of real IPHRs in vast communities of patients and caregivers would require the alignment of many interests and the involvement of multiple stakeholders. Moreover, evaluating the system in real settings ("in vivo") would require to focus on the so called "unintended consequences" of Health Information Systems (Harrison et al., 2007), which could entail serious problems of information overload, information filtering and interpersonal conflicts.

For this reasons, this contribution is rather aimed at presenting the research concept of IPHR, and at supporting it by proposing a first full-fledged implementation that addresses all the high-level requirements, as well as many of the functional ones, that derive from the IPHR concept, as its feasible and cost-effective proof-of-concept. Therefore, this work can be seen more concretely as a work addressing the research question whether the IPHR concept is technically feasible and capable of providing the complex functionalities of communication and content sharing described in the previous sections than proving its social adoption and usability.

Our contribution to this question is the realization of MedIcona. This is an open-source, free, Drupal-based IPHR that integrates a visually and conceptually rich way to annotate the record's content and resources (which was just outlined here and presented in more details in (Cabitza et al., 2013)) with sophisticated yet user-friendly mechanisms to create forms, upload documents, share health content and support message exchange about this content.

Due to space limitations, we could focus only on the basic architecture and on the communication-oriented features of MedIcona. In so doing, we provided information useful to replicate this model also on other similar and equally affordable content management systems (e.g., Joomla, Wordpress) and, indirectly, to demonstrate the economic affordability and technical sustainability of the three scenarios presented in Section 3. This choice forced us to leave outside other important features of MedIcona, like the integration with external Web resources for knowledge dissemination and appropriation, the rich chart visualization capabilities and the timeline-based access to the content (see Section 2), as well as to overlook the security-oriented aspects of this record, i.e., a feature that a health record should obviously exhibit as a primary concern and core feature. Thus, in regard to this latter aspect, we hint at the fact that our prototype currently guarantees security and confidentiality through the fine grained configuration of the access control modules used to implement content sharing and user permissions. Moreover, contents that are uploaded to MedIcona are encrypted during the upload phase with no direct intervention of the user. This basic support will be improved in three further ways: by (i) implementing an intrusion detection system (IDS) that could be flanked by (ii) a "ban by IP" system, and (iii) by implementing techniques to avoid SQL-injections that some Drupal modules already address.

As first contribution in demonstrating the feasibility of the IPHR concept in the context of care networks and personal health management, we are

currently offering the system to anyone interested in trying and testing its more innovative functionalities at the Web address http://tinyurl.com/MedIconaBeta. The full functional evaluation of the system in real settings will be addressed in further researches that will be aimed at testing which scenario of those outlined in Section 3 is more feasible and promising with respect to its economic sustainability in the long run.

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