A Web2.0 Platform in Healthcare Created on the Basis of the Real Perceived Need of the Elderly End User

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Abstract. The elderly care is characterized by integration of health and social care, is performed by several different agencies, requires a continuum of assistance and not episodic approach. These considerations has led us to overcome the traditional ICT approach done by several applications connected with property mechanism towards new solutions proposed by web2.0. We think that a federative platform can support the elderly needs (detected through focus groups) providing them web2.0 solutions in health care. The main features of the federation are: publishing/subscribe, messaging and signaling. These dimensions allows elderly to participate actively in their own healthcare through the access to their own health and social record, the composition of their own health and social space, and the participation to social networks for remaining socially active. Moreover, the process of dis-intermediation is also allowed. More emphasis is posed in the federative platform for the governance of the services as requested by elderly.

Keywords: Web 2.0, Medicine 2.0, e-Health, personalized healthcare, EHR.

1 The Early Approach to Elderly Care and the New Challenges in Web2.0

Among the Italian cities Bologna (Italy) has the highest percentage of elderly above 64 years (26.7%). Families with at least one member over 64 years are 38% of Bologna's families. Families with only one member over 64 years are almost 17% of the families, if we consider only elderly with more than 79 years the same percentage is 7%. Several projects for elderly using ICT have been implemented in the last few years in Italy and especially in Bologna [1]. These projects have been generally called e-Care projects. The goals of the traditional e-Care network are the followings: to connect the stakeholders in the socio-sanitary processes; to share the information during the treatment, to provide a more complete and integrated care using ICT solutions; to integrate health and social services; to collect citizens' health information through the network. These projects consist of several applications aimed to communicate with each others in a peer-to-peer connection, so they tend to build up several data silos with the same data but with different functions. Emphasis is posed on the data exchange and not on the collaboration activity needed for caring people in a

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multi-agencies environment. In our new project, called OLEDS and co-founded by the EU [2], elderly are provided at home with a simple device managed by a remote control. The system is connected to the TV and to a VoIP telephone; elderly suffering from coronary artery disease are monitored with blutooth easy-to-use telemedicine devices. At this state of the project 30 elderly, 4 volunteers associations, doctors and social workers are experimenting the platform; by the end of the year others 70 elderly will be engaged. The main aims of the project are the followings:

1. To overcome the traditional 1-1 relationship in a one 1-many: in this context we try to promote the aggregation of social networks through the utilization of thematic channel managed by animators;
2. To engage different stakeholder with different responsibilities and associated to different organizations (institutions, volunteers, private sector);
3. To provide a complete care for elderly both on social and health side. For elderly health space cannot be separated form the social space;
4. To manage the "jam of data" collected from elderly: the concept of numerical data in a relational Electronic Health Record now is wider; the information that describes the health or social state of the elderly are composed of different type of data, for instance numerical data coming from devices, videos, images, speech diaries, ...

On the other hand our experiences have led us to modify the approach normally used because we think that the problem is not to propose a particular home devices, but an organizational change driven by ICT and web 2.0. From an organizational point of view:

1. Essentially the elderly care is a multi-agency activity: this commitment doesn't allow to impose solutions it has been done proposing singles vertical application and a middleware layer for the integration; but it requires an activity based on the co-production;
2. The care of the elderly must respond to a complex long term conditions rather than rely on the traditional approach of episodic care; whereas we need to consider the continuum of care.
3. Engagement of elderly and stakeholders in the care processes.
4. The "www" of the elderly is the little but great world of relationships and the main scope of the platform we are going to explain is the representation of this world using the technological benefits of the web2.0.

We have observed the following characteristics of multi-agency care and of the contexts in which shared technical infrastructure and new working practices are being constructed: the participants not only belong to different agencies but also have the different value sets, priorities and perspectives; the policy drivers and management imperatives that bring the parties together often imply or demand second order rather than incremental change; the nature of the health and social care relationships make issues of governance of practice and of information paramount; often the technological systems for care people are "user centric", this is an improvement compared to "function centric approach", but there is no health information out of patient-doctors relationship. We noted that the nature of the problem requires the engagement of several institutional agencies in conjunction with volunteers organizations and the social capital they can bring and the new marketing perspective introduced by private sector requires a new definition of technological system. This new technological

system is different from the traditional way considered as several solutions (web or legacy) closely interconnected. For these reasons, inside the project, we have introduced three "technical" terms in response to what we have discovered from contacts with the realities of the provision, delivery and use of service to support elderly people in Bologna:

- The projection orientated approach to systems representation
- Federability approach in designing and delivering services involving multi-agency
- The service orientation to systems organisation

The first one is a response to the need to maintain accessibility and participation in the face of complexity, the last two are a reply to the heterogeneous, multi-agency nature of the context we are engaged. Our commitment to user centered design removes the possibility of segregating policy making, requirements capturing and design spaces. We have to create a space in which these processes co-exist and co-evolve. Responsibilities remain distinct and "boundary objects" are required to mediate and facilitate mutual sense making. This is the purpose of the projections and the way they remain distinct but interrelated at both semiotic and formal levels providing a potential bridge between the languaging and the engineering domains. During the last decade, a large body of projects and technological realizations have been carried out aiming at creating e-Health and telemedicine technologies. There is a relatively low practical application of them in every day practise. One limitation is that, even if theoretically perfect, the realized innovation are far from the perceived need of the final user and from its ability to use them. In this context we have met 70 elderly subjects (mean age: 78+/-6 years old, M:W=1:1.2) in recreational meeting centers in the city of Bologna administrating them a specific questionnaire created to understand their technological skill and their perception about new technologies potentially useful for the management of their health. The preliminary analysis of the questionnaire show that the interviewed elderly are relatively interested in the possibility to use new technologies to manage their health care. In particular they could be interested in technologies that are easy to be used, and could automatically furnish information such as weight, blood pressure or even a basal electrocardiogram. The most part of interviewed are able to use the standard electronic tools such as the phone, television remote control, the kitchen tools and the washing machine. The most part of them measures their blood pressure with hand or automatic sphygmomanometers, but they don't use or don't know the existence of the most common e-health technologies, or they don't surf the internet.

2 The Federative Platform as Approach for Web2.0 in Healthcare

The kind of problem described in the previous paragraphs cannot be dealt by using the classical enterprise approach made of property solutions, deployed on the web, closely integrated with proprietary mechanisms. It is because of these challenges: multi-agency solution, continuum of care for elderly, engagement of elderly and stakeholders in the care processes; that we refer to a federal approach which both supports and depends on trust and co-operation between agencies allowing them to

maintain their individual relationship with clients and responsibility. In this vision, the processes which maintain, refine and evolve the rules, scripts and practices inscribed in the infrastructural system are seen as an integral part of the use and governance of the supporting information and communications services. A technologically advanced e-Care environment implies a highly distributed collaborative network, composed of heterogeneous and autonomous nodes: all of which are involved in supporting the elderly and delivering or orchestrating services. We are not proposing a conventional application but we are defining a set of services that users may compose in a creative way (within limits imposed by the service logic) to compose their own environment. In the infrastructure we are building, different components (services) may be fit. Services can be developed at any time, when their need arise. Using the conventional «hub and spoke» metaphor, the nucleus of the architecture is the service hub which provides the means of connecting user systems to services systems. The functions which the hub provides are relationship and provisioning services; registration and publication services; event, process and transaction services. The core concept of the OLDES architecture is the service hub which provides the means of connecting user systems to service systems. Additional notions are: (1) Federation is achieved through hub to hub connections and the sharing of third party services; (2) The hub provides the core coordination services which are associated with "middleware", these are: "Portalling" i.e. publication, syndication and organisation of contents; "Switching" i.e. process coordination within and across boundaries ensuring that sequences of events and transactions are managed; "Indexing" i.e. the management of identifiers, tokens, authentications and relationships. (3) The concept of provisioning (consents and capabilities) is extended to apply not simply to role based user access to named resources but also as follows: (a) Services require explicit provisioning to make use of the outputs of other services, (b) Any instance of provisioning involves a link between a source of (sensitive) data, a sink – or user - of the data and the subject of that data: a three way relationship role and relationship based access, (c) The notion of a service session provides the final provisioning concept where sessions are declared and audited by class, e.g. emergency, ongoing case, etc. We think that this architecture can respond to a challenges proposed by web2.0 in health care. In this platform the concept of federation and the associated components allows to elderly to autonomously use technology to access personal information like EH/SR, to manage their personal health, for nurturing social inclusion through social networks. On the other hand, stakeholders belonging to different agencies can participate in the care process in a collaborative way using the tools for composing the services requested by elderly and met on the network through the engine for knowledge search. The key requirement that is being addressed in this architectural approach is one of governability. In care and development environments, information may be accessed and used only on the basis of informed consent and for the purposes intended in the granting of that consent. Not that this is the antithesis of the web2.0 concept of complete absence of accessibility constraints on data about content or use of content. These particular issues of governability require explicit representation at the architectural level because they are an essential part of the requirements and policy discourse. This is an essential characteristic of what in the federative platform we refer to as "service orientation". Issues of capacity, availability and safety may be treated as a technical abstraction and relegated to the negotiation of the service platform provision relationships. In

summary then, the OLDES service platform provides a potentially extendable and federable environment for the brokered delivery of services. To better explain we can introduce the following two logical components:

System Management functions: functions used for the control of the system.

Service Management functions: functions needed to integrate with other hubs, allowing the access of new agencies, the exposition of services and of contents.

Features characterizing the federative platform are:

"Publishing and Syndication": this is the concept of making own information accessible to stakeholders which have necessity to access; in this vision the communication of personal information is an active action based on recognition by the parties of the need to inform and the desire to share and in which the subject of information is an informed and active participant;

"Messaging": in this platform the concept of message does not allow the exchange of data; the message isn't only the vehicle for building or maintaining data base, but it is the way for alerting users also.

"Signaling": it is the observation of the events in the federation. It produces marketing (for profit and no-profit organizations) because the agencies and volunteers organizations can produce new services on the basis of the usage of the services by end users, observed using signaling functions.

The use of data in the federative platform is worth a further discussion. The platform needs not only data produced within its boundaries but also data that can be produced and owned by other agencies within the federation. A specific service (or set of services) must be responsible of recovering information from different repositories belonging to different agencies and compose them in a transparent way on the user interface of the care-giver. From a logical point of view, we have to introduce a service for data management which scope is not to aggregate every type of information in a single data base, but to extract information and compose a specific record from federated databases. The notion of governance which has been used so far applies to the definition, commissioning, delivery and evaluation of service. It is concerned with the means and the mechanisms by which authorized personnel is able to ensure that the service environment is directed and operates in an appropriate and effective way. Within this concept, we can distinguish a further aspect or level of governance which applies to the information that is generated and interpreted in service processes, particularly when they are mediated or supported by electronic means. The importance of this distinction in the governance rests on the idea that there are information and communications services which are shared by a number of higher level, care services, and, through sharing these underlying services, higher level services are able to co-ordinate their operations. This continuing independence and distinctive identity of the participants means that the term "integration" is no longer appropriate. This coordination of independent entities, through the sharing of (third party) information and communications services, is the core concept of Federability and, as such, can be seen to be closely associated with the sort of service oriented approach we are describing here. This leads us to the imperative we face: agencies within clinical and social care, the voluntary sectors and the commercial sector are, and will remain, independent but only if they co-ordinate and co-operate that the gaps

between needs and available resources in the care of the elderly can be addressed. The core purpose of this service infrastructure is to make this co-ordination possible [4].

3 The Contribution to Web 2.0 in Healthcare for Elderly

As a contribution to Web2.0 in healthcare we think that the implemented platform can reply to the request of providing to the patients some tools for promoting their participation in the care process. In particular, taking [3] as a starting point we introduce some dimensions that describe how some functions can provide the autonomy to the patient in his "collaboration" with stakeholder to improve their own wellbeing. The emphasis is posed on the autonomy of the patient in searching and using health services on the net. The experiences done has demonstrated that when we design ICT system for health using the capabilities of the internet we have to keep in mind the user target and the method for facilitating the entrance of the technology in patients' houses and the engagement of different agencies involved in the care process. The first feature we would like to analyze is the EHR built by professionals but accessible by patients. In this context, we prefer to refer to an Electronic Health and Social Record (EH/SR) for stressing the concept of collaboration among different agencies discussed above and the concept of elderly wellbeing that does not separate the health activities from the social ones. In this context we consider an EH/SR personally controlled by elderly, and build by professionals and by elderly themselves as a kind of simplified health space. The main areas of the personal health space are:

1. Questionnaires for specific communication with professionals. In this area elderly are driven to fill suitable questionnaires about social state or about specific chronic disease.
2. Observational and narrative speech diary. These features give to the elderly an opportunity to record a free speech diary about their health problems or social anxieties.
3. Visualization of data coming from devices; data coming from telemedicine devices are visualized and presented to elderly.
4. Personal booking and appointment; elderly with the help of volunteers, record and remember personal appointments.

Of course, professionals complete the areas of the EH/SR of the competence of doctors and social workers. Another area of participation proposed by web2.0 is the opportunity for elderly to participate to social networks. In the context of this platform social networks are thematic channels proposed by animators that engage elderly in conversations or entertainment. The contribution of different agencies in the organization of thematic channel is an important challenge to the utilization of the platform by elderly. An interesting feature proposed in [5] describes a special form of disintermediation where people who search health information on the web receive the guide from "apomediaries"; they are agents (people or tools) which "stand-by" and guide the users to services. It is noted in [6] that the process of disintermediation can follow a route from intermediation to disintermediation when the user reaches a sufficient autonomy, but people can return to intermediation, so the relationship with intermediary is not ended. The federative implemented platform can be considered a mix of brokerage and disintermediation and is stressed the dynamic previously discussed.

The elderly expresses a strong request for socialization and this is provided by web technologies. In this platform apomediaries are really the volunteer associations and the automatic tools that help elderly to extend their trust relationship and help elderly to obtain the specific information they need (the access to the health space, the request of services). But in this mechanism we have to consider that EH/SR in the platform is centered on the elderly-doctors relationship. This implies a trust relationship, so the intermediation-disintermediation process needs both a brokerage activity performed both by tools and by intermediaries for guiding elderly and stakeholders to the choice of the request information. On the other hand for the stakeholders the process of analysis of information produced inside the platform and the search of information is very important [7]; but we would like to note that the different information exchanged also produce a sort of marketing where stakeholders can generate new services and new thematic channel on the basis of the real requirements of the elderly. In fact at the core of this disintermediation tool is an advanced profiling, matching and targeting system that will allow to continually enhance the relevance of the content offered to the targeted audiences, the degree of their usage and participation, as well as the efficiency and effectiveness of the thematic channel production, moderation, assistance, support and system availability processes. This system is based on contextual, behavioral and social networking targeting, making use of knowledge/intelligence extracted automatically from unstructured content (thematic channels, speech diary, communication between all the stakeholders of the system, questionnaires), from historical analysis of user – system interactions and from sensors data received from the medical sensors. The extracted knowledge along with other specific enterprise knowledge (knowledge contributed by the experts of the federative platform; definition of alarms, of triggers, of processes, best practices, etc.) is maintained in a dedicated Knowledge Base. Within the federative platform, all the interactions between the stakeholders are formalised in well defined models (events, tasks, processes, best practices) that will take advantage of the technologies developed and allows the presentation of specific scenarios. For this reason, the mechanisms of signaling and logging play an important role because they allow the generation of elderly profile and the health scenarios used by stakeholder for better care the patient or for proposing the services requested.

4 Conclusions

In several years of elderly care projects we have learned that the elderly care cannot be addressed through en episodic care approach, it must be a continuing assistance both in the health care and in the social world. The concept of wellbeing that we are pursuing does not allow these two aspects of care to be separated and treated independently. This is more clear if we think that the care of elderly is done by health institutions and social workers; and the “little” world of elderly is done by the trust relationships with doctors, social workers, family, friends, parishes, volunteers organizations; and a real system of care cannot exclude one of these components of the elderly life. For this reason we thought to work about the organizational change necessary for responding to this understanding. This led us to search the novelty brought by web 2.0 and we proposed a federative platform with the features of publishing and subscribe, messaging and signalling. In this context, the platform responds to the

requests of elderly (recognized from the outset of the project through focus groups) by providing an infrastructure capable of supporting the operation and governance of a dynamic and participative e-care, and this implies a requirements for regulation, governance, consent or confidentiality, and the important issues of governability is an essential part of the requirements and policies commitment. The federative platform uses a specific set of web tools for responding to the request of generation of content by users and the power of the platform is used in order to personalize health care, collaborate, and promote health education such as connecting elderly with same interests or chronic disease and improving an individual's value from health and social care. The EH/SR is built by professionals, but is accessible by elderly; and nearby a sort of health space is built up where elderly can record a speech diary and where health and social questionnaires are proposed. In the platform, the usage of the data allows a more strict collaboration with stakeholders because information is not a property features of a data silos. Moreover the platform allows the participation to social network animated by volunteer; this allows elderly to be social active and in relationship with other people. The mechanism of generation of new contents, services and social networks is composed using the automatic tools that analyze the requests performed by elderly. In this context of dis-intermediation elderly can personalized own health and animators can compose their new services. On stakeholders' side the data gathered (questionnaires, usage of the services, data from telemedicine devices, speech diary, …) will be treated by automatic tools for composing elderly profile and for proposing scenarios for better care patients.

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