A FRAMEWORK FOR ADAPTING A PATIENT-CENTERED ENVIRONMENT THROUGH MASHUPS

Payam Sadeghi, Morad Benyoucef and Craig Kuziemsky
University of Ottawa, Telfer School of Management
55 Lourier Avenue East, Ottawa, Canada

ABSTRACT

In this paper we present a framework which encourages patients and other actors of a healthcare process to collaboratively develop personalized online health applications according to their specific and on-going needs and requirements. We propose mashups, a web 2.0 technology, as a foundation for our proposed framework. In addition, we recommend a system development process which can be considered for using our framework, where all the actors of the healthcare process develop their own healthcare environment collaboratively. We believe that our work can bridge the gap between healthcare providers and patients with the aim of providing a user-centered environment that fulfills the targets of empowering users throughout the healthcare process.

KEYWORDS

Health 2.0, Web 2.0, Mashups, User-centered System Development

1. INTRODUCTION

The 2001 Institute of Medicine (IOM) study 'Crossing the Quality Chasm: A New Healthcare System for the 21st Century' described how our healthcare system fails to provide consistent, high quality care to all people who need it (Institute of Medicine 2001). In particular the study pointed out that the healthcare system is poorly organized to meet the challenges it faces as healthcare delivery is changing from care provided by a single provider and setting to care provided by multiple providers across multiple settings. Two of the key recommendations from the IOM study are the development and delivery of care by high performing patient centered teams in order to coordinate care across different diseases, sites and services over time, and the use of information technology to enhance healthcare delivery. However those recommendations are a challenge to implement as healthcare is one of the most knowledge-intensive sectors where different models and technologies are being developed in order to effectively deliver information across the healthcare process with the aim of providing better services and treatment to patients. Furthermore, healthcare delivery is evolving from disease-centered to patient-centered where patients are active participants in their healthcare process, and the patient's participation and expertise are greatly encouraged and valued. Current healthcare policies advocate greater involvement of patients in self-care (Timpka et al. 2008) due to the fact that optimal outcomes of healthcare interventions are achieved when patients become active participants in the healthcare process (Bos et al. 2008). For this purpose, Web 2.0 technologies, also called *collaborationware*, have been increasingly adopted over the past few years by many care givers and health providers for creating a patient-centered environment where both care givers and patients are able to directly communicate with each other and work on possible treatments collaboratively, share and exchange health information, provide emotional support and awareness for improving the quality of treatment, patients' health and well-being. However, the amount and availability of health information is increasing and the number of health applications and services available on the web is growing rapidly. In addition, people's use of the web as a primary source of health information has increased dramatically (Karkalis & Koutsouris 2006). The implication of that growth in information and web usage is that information integration and collaboration on a large scale has become complicated. Proactive delivery of the right information to the right person at the right time is particularly important. Overall there is an increasing demand for personalized health systems facilitating the effective

management of information, simplifying communication and collaboration, and supporting miscellaneous applications and services for meeting different users' specific requirements and ongoing needs.

In order to properly address the aforementioned challenges, a feasible framework and a methodology need to be developed to advance information integration and interoperability of health applications in a *controlled manner*. Hence, a systematic structure for capturing the broad perspectives on health service delivery (Timpka et al. 2008) and supporting multi-disciplinary decision-making should be considered where the services are customizable, adaptable to multiple settings, and module-based. The framework and methodology should not only encourage the patients to personalize their environment and generate content, but all the actors of the healthcare process are encouraged to customize the healthcare environment according to their specific needs and requirements. For implementing such framework methodology, all the actors of the healthcare process are provided with a sufficient set of flexible tools in order to tailor the health applications, directly communicate with one another and therefore work on development collaboratively. By this, patient empowerment will be significantly improved since every entity (i.e., actor) in the healthcare process is focused on increasing value for the users, especially for the patients. The main result of such a collaborative environment could be a *truly personalized health environment* where users' needs are based on facts and actual demands rather than assumptions and limited predictions, and this can ultimately lead to a paradigm shift in patient-centered health systems. Among several Web 2.0 collaborative technologies, *mashups* can provide an adequate foundation for implementing such framework and methodology.

The value and capabilities of mashups in the healthcare domain have already been studied and demonstrated over the past years (Greenshpan et al. 2009). Ohad Greenshpan et al. have proposed mashups as a leading technology for facing the emergent needs in the Health 2.0 (Health 2.0 is used nowadays to designate Web 2.0 when applied to healthcare) era. They also presented a mashup-based patient-centric Extended Personal Health Record system (xPHR), called Medic-kIT, in order to demonstrate how mashups could assist in coping with challenges in the healthcare domain. However, we are not aware of any framework and methodology that clearly show how mashup composition should be implemented in an effective and efficient approach and how its architecture should be designed according to the changing needs of all actors of the healthcare process.

The contribution of this paper is a mashup-based generic framework accompanied by a recommended system design process to serve as a model for implementing a web-based patient-centric environment. In our proposed framework the idea is not only to consider patients' needs and requirements, but also to gain a greater value when all the entities of a healthcare process are considered and when they all work on the development of a health environment collaboratively and in a *structured* manner.

This paper is organized as follows. Section 2 describes the evolution of mashups and their capabilities. Section 3 describes the relationships among different actors of the healthcare process in the form of a value web analysis. In section 4, our proposed framework is presented together with an explanation of its structure and components. Section 5 presents the possible development process for using our proposed framework. Finally, Section 6 presents our conclusions.

2. THE EVOLUTION OF MASHUPS

Mashups represent one of Web 2.0 technologies and they are considered a fast-growing integration approach in the field of data management. The evolution of mashup technology is believed to be the next stage of Web 2.0. The aim of mashups is to reuse the existing data sources or Web applications from heterogeneous sources and combine them into a single integrated application. As discussed in (Koschmider et al. 2009), the idea behind the term mashup is not new and in fact the integration of disparate resources has always been an issue during the software development process where some data and functionalities are provided by external systems, and mechanisms are presented in order to specify them properly. However, mashups are gaining popularity mainly because on one hand, as described in (Jhingran 2006) and in (Abiteboul et al. 2008), the number of applications on the Web is growing very fast, and therefore there is a need to combine them in order to meet users' specific requirements. On the other hand (Koschmider et al. 2009), through mashups even non-technical people are able to create new content and represent resources without much effort or knowledge of programming languages through enhanced user interfaces, and therefore the main emphasis of mashups is on user-driven, simple and fast integration development and specifications. In addition, as

mashups pull and integrate data and services dynamically from different sources, they can grow and evolve over time. Also, since all mashups inherently take advantage of interoperability, each user is able to convert his or her mashup from using one data source or service to another, and as a result users' needs are better satisfied in a timely manner. Despite the fact that the number of mashups is increasing rapidly, there are only few applications of mashups in healthcare. As an example and as mentioned in Section 1, Ohad Greenshpan et al. proposed a mashup-based patient-centric xPHR system in order to assess the potential of latent effectiveness in the mashup approach (Greenshpan et al. 2009). Their system includes components of three main classes namely Medical, Personal, and Collaboration and it is part of a larger system that provides personalized monitoring of patients with notification on anomalies to relatives and caregivers. They suggested mashups as a leading technology for the requirements of Health 2.0 since they provide a great potential to improve the quality of care through empowering patients by delivering patient-centered and easy-to-use solutions. We strongly support their suggestion and we believe that mashups will help all healthcare actors to customize their applications based on their ongoing needs and situational problems. As a result information is adapted easily into exactly the form that actors need, and subsequently healthcare providers and organizations are able to reduce development time and cost and can lower the cost of customizing information for individuals. Furthermore, we believe that a generic framework is required in this case in order to clearly exemplify how mashup-based patient-centered applications should be developed in an efficient and effective way. As Jin Yu et al. argued in (Yu et al. 2008), comprehensive frameworks are lacking in mashup development to speed the overall process and to enable inexperienced end-users to mash up their own Web applications. Even though there are some frameworks such as those discussed in (Yu, Benatallah, Saint-Paul et al. 2007; Yu, Benatallah, Casati et al. 2007), we are not aware of any generic development framework specifically developed for the healthcare environment. A customized generic framework would encourage healthcare actors to collaborate on the development of mashup-based health applications, and it would also bridge the gap between healthcare providers and patients with the aim of providing a patient-centered environment that fulfills the targets of empowering patients during the treatment process and improving their health conditions. In order to devise such a framework, we need to identify the main entities of a healthcare process and define the value that each entity is able to provide throughout the development process. We call this course of action Patients' Value Web Analysis, and the following section provides more details about it.

3. HEALTHCARE VALUE WEB ANALYSIS

Healthcare processes consist of various actors working together with the goal of improving patients' health condition and well-being. In order to develop a healthcare system, the first step is to identify the actors of the healthcare process and define their relative importance as well as the value which they are able to provide throughout the delivery of healthcare services. For this purpose, we adapted the Value Web Analysis (Kornak et al. 2004) as a modeling technique for capturing, visualizing, and then analyzing the network of interactions to define the value of each participant to the network. The value of each participant is defined based on three dimensions (Kornak et al. 2004): Informational Value (I), Intangible Value (T) and Economic Value (E). Informational value, in our case, includes the level of information and exchange of content that each actor of the healthcare process provides or receives; intangible value includes the level of influence, opinion and support or similar unquantifiable values among the actors; and economic value describes the exchange of services or products, usually involving financial transactions. Figure 1 shows the possible actors of the healthcare process together with the potential interactions among them.

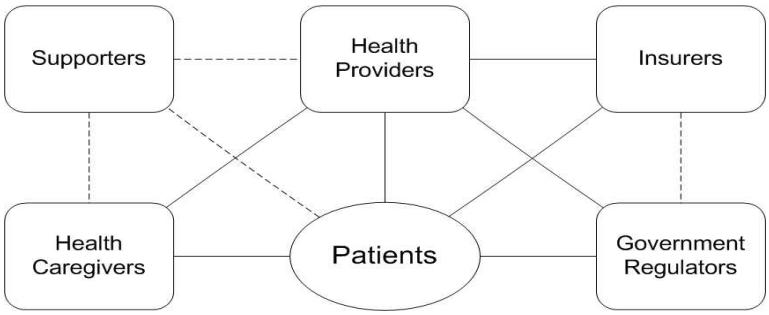

Figure 1. Healthcare actors and interactions

Solid lines between the actors of the healthcare process indicate tangible interactions among them at a close level. Dotted lines denote non-financial relationships that are mainly influential, meaning that they may influence actors' decisions. Now that the possible actors of the healthcare process and the value dimensions are specified, the next step is to create a *generic value matrix* in order to show how two actors possibly interact with each other in terms of informational, intangible, and economic values. Figure 2 shows the generic value matrix of a healthcare environment.

Table 1. Generic value matrix for the healthcare environment

		Outbound: Value Delivered to Others					
		Patients	Health caregivers	Health Providers	Supporters	Government Regulators	Insurers
Inbound: Value Delivered from Others	Patients		I, T, E	I, T, E	I, T	-	I, E
	Health caregivers	I		I, E	I	I	-
	Health Providers	I, E	I, E		I	I, T	I, E
	Supporters	I	I	I		-	-
	Government Regulators	-	I, E	I	-		I
	Insurers	I	-	I	-	I	

As shown in Table 1, almost all the actors of the healthcare process interact with patients during the treatment process: health providers provide informational and economic (health service) values to patients; healthcaregivers provide informational and intangible values to patients; supporters (including family, friends, peers, etc.) provide informational (e.g., patient's background, habits, reactions, etc.) and intangible (e.g., opinions, support, etc.) values to patients; insurers provide informational and economic (insurance plan) values to patients; and government regulators may provide informational (changes in regulations) and economic (e.g., OHIP, financial support, etc.) values to patients. It is important to mention that patients may also provide different values to the other actors at various stages of the treatment process and therefore values are being provided from both sides. On the other hand, values are not being only provided to/from patients; although each actor of the healthcare process may provide values to various actors during the treatment process with the aim of ensuring optimal results for the patients and therefore improving patients' health conditions. As indicated in the above table, both healthcaregivers and health providers provide a maximum level of values to patients, and therefore they can be considered as the key actors of the healthcare process. In addition, supporters and insurers are the next actors in the process who provide an average level of values to patients. We believe that actors who provide an average and above average level of values to patients should be involved during the development of any patient-centered environment. On the other hand, since patients are not the only users of a healthcare environment, the same idea should be considered during the development process. This means that, for example, while specific applications or services are being developed for health providers, actors who provide average and above average level of values (like patients, healthcaregivers, government regulators and insurers) should be involved during the development process in order to provide inputs and opinions for facilitating better interactions among them. As a result, in any

development of a patient-centered environment, the values of each actor should be evaluated, and based on their level of values they should be involved at different stages of the development process. The above analysis may differ in different health settings or countries, and it can be modified accordingly.

4. FRAMEWORK PRESENTATION

Now that the capabilities of Mashups for developing a patient-centered environment and the actors who are directly involved in the delivery of health services are described, a generic framework for adapting a patient-centered environment will be presented. As discussed before, the idea behind the framework is to provide an environment for users to directly communicate and collaborate with each other, personalize their healthcare environment according to their needs, while health information and applications are effectively managed by all the actors of the healthcare process.

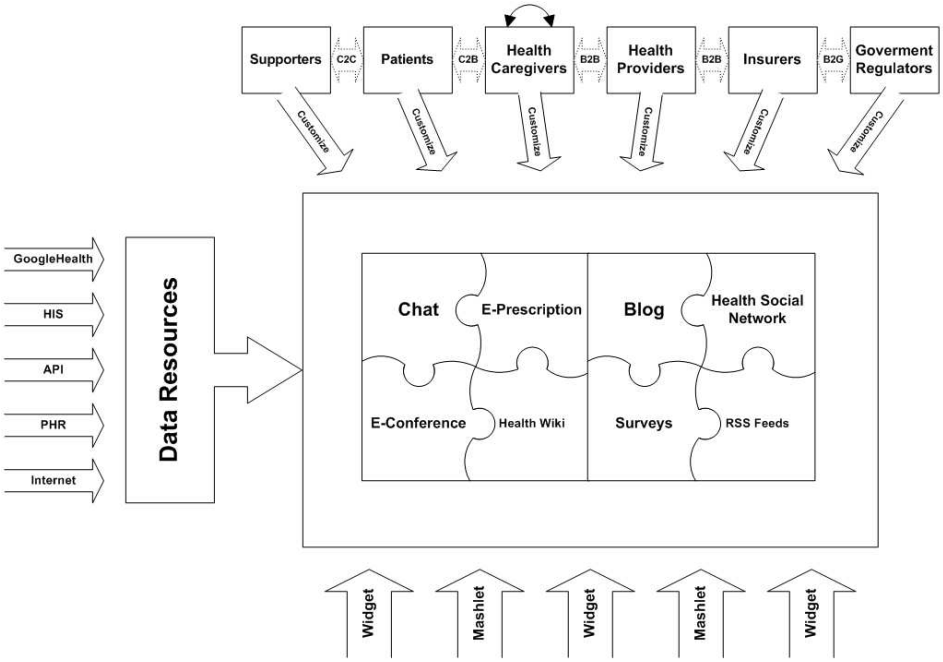

Figure 2. Mashup-based framework for web based patient centered environment

As shown in figure 2, the proposed framework consists of four main components. At the top, the main actors of the healthcare process are located and the relationships among them are defined based on the *supply chain operations reference model* (Scott Stephens 2001). Within this well-accepted reference model, patients and their supporters are considered as customers (C); healthcaregivers, health providers and insurers are considered as businesses (B); and government regulators are considered as government (G). Through mashup technologies, all the actors of the process are provided with a set of Web 2.0 tools and technologies throughout the design and development processes in a way that they can customize and tailor the web-based environment according to their specific and ongoing needs and requirements, while they are able to directly communicate with each other for better realizing and discussing their needs and difficulties. Direct communication among all the actors may greatly improve the efficiency of the development process since all the necessary information is being shared and made available in a collaborative manner (Hoegg et al. 2006). As a result of involving the main actors of the healthcare process early in the design phase, a more effective and usable system will be implemented (Pilemalm & Timpka 2008). In such a bottom-up approach, where patients and other actors of the healthcare process are the actual creators of healthcare services and applications, patients are considered as partners and their expertise is greatly valued, and other actors are able to directly examine which applications are being incorporated by the patients in order to better understand the

patients' needs and consequently provide them with sufficient ways of performing a task or using a service. Shifting to such a direct partnership model may throw light upon *shared care* which will bring greater linkage between health system players for coordinated patient treatment (Millar 2004). This, in fact, is one of the main characteristics of the evolving healthcare delivery model as discussed in (Charles et al. 1999).

The center of the framework is the actual environment where different Web 2.0 technologies and health applications are being offered to users in a way that they can utilize and customize them according to their needs and preferences. Some of the most popular applications demanded by patients and other actors of the healthcare process are discussed below.

Chat Component: As discussed in (Bos et al. 2008), to achieve a true patient-centered environment, a *bi-directional* contact between patients and healthcaregivers is necessary. For this purpose, chat applications can be incorporated by either patients or healthcaregivers to directly share health information and experiences with one another. This component can also be used by patients for finding other people in similar health conditions, through health chat rooms, for gaining mutual support. It is important to mention that all the available Web 2.0 technologies and health applications can be incorporated by any actor of the healthcare process regardless of who they are, and they are not limited only to patients or healthcaregivers.

Social Network Component: A health social network is a website (which can be incorporated as a component) where users are able to find heath information at different levels ranging from a basic tier of emotional support and information sharing to consulting with healthcaregivers. One of the key values of health social networks is the potential to find others in similar health situations and share information about conditions, symptoms and treatments (Swan 2009). According to PatientsLikeMe, "patients who choose to explicitly share health data within a community may benefit from the process, helping patients engage in dialogues that may inform disease self-management (Frost & Massagli 2008)".

Blog Component: a Blog is a two-way content management tool where people are able to post their thoughts, ideas, suggestions, and comments (Murugesan 2007) which are presented in chronological order with the latest entry listed first. Blog entries could include information on prescriptions of medication, daily comments about health incidents, and even measurements and examination results (Karkalis & Koutsouris 2006). There are currently many medical/health related blogs available online such "the Cancer Blog" (Weblogs, Inc. 2010) and "Clinical Cases and Images" (Dimov 2010), where many patients and health professionals provide information on different health topics, and share their experiences and emotions.

Wiki Component: a Wiki is a collaborative and expandable collection of interlinked web pages that allows any user, including patients, to quickly and easily add, remove, or edit content (McLean et al. 2007). Like blogs, wikis can be used as a source of information and knowledge where medical and health related dialogue and information can be shared among all the actors of the healthcare process or specific project groups. There are many successful medical wikis nowadays such as Flu Wiki, Wiki Surgery, etc.

At the bottom of the framework, widgets or mashlets components are presented which are basically applications intended for user-specific needs. Mashlets can have their own graphical user interface or be presented as Web Services. Examples of mashlets are a "To do list" widget, an "Image viewer" widget, a "medical data analyzer" widget, or even an Electronic Health Record (EHR) widget. Here, users are able to drag and drop mashlets onto the mashup environment and interactively configure them.

On the left side of the framework, data sources are in place as suppliers of the mashup environment. As argued in (Cheung, Kashyap et al. 2008), optimal value will be gained when mashups can be created across the resources. This means that in order to gain the maximum possible value from our development, we need to consider all the health resources including Health Information Systems, Internet-based Applications as described above such as Patient Health Records systems (PHR systems), etc.

5. DEVELOPMENT PROCESS

The final aspect of our framework is using it for system development. However system development is challenging as the different actors will have different needs and different values identified through the value web analysis. Thus there will be multiple implementations of the framework. In order to accommodate the needs of different actors we advocate using an iterative, user centered systems development method which is in fact based on collaboration between all the actors of the healthcare process. Since the objective of the proposed framework is to provide a truly user-centered environment, the core development group should

consist of the main users, such as patients, and those who provide the maximum level of values to users, like healthcaregivers and health providers. For this purpose, visual mashup development tools, like Yahoo Pipes (Yahoo! Inc. 2010), should be offered to end-users where various features and simple composition approaches are included for streamlining the mashup development process. The following iterative process can be considered for the development of the proposed framework.

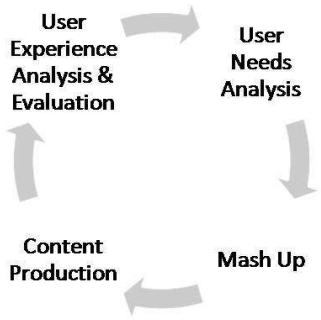

Figure 3. Iterative user-centered development process

As shown in figure 3, the iterative design process consists of four phases described as follows:

User Needs Analysis: At this phase, the preliminary requirements and specific needs of users are identified and documented in details. These include their information needs, values, preferences, data types, services, and possible required support; with regard to patients, information of their physical and health conditions as well as some information about their family and friends. Since a large amount of information is being gathered and analyzed at this phase, we recommend that all the actors who provide information values to users be involved throughout this process. For example, for patients, the following actors should be considered for better realizing the patients' needs: healthcaregivers, healthcare providers, supporters and insurers.

Afterward, the existing Web 2.0 technologies, which can be used to implement different functions for satisfying users' identified needs, are being discussed with users in a simple and understandable language. That is where users are practically considered as partners in the design of the healthcare environment. By this the healthcare environment, which is being developed by users, will be regarded as useful since its technologies and components are being defined during their default state, and user engagement will be improved significantly (Alexander 1979). It is important to mention that at this phase, face-to-face interviews, online chatting, surveys, and cultural probe methods (Hassling et al. 2005) can be used to communicate with users for establishing their basic requirements and sufficiently understanding their needs.

Mashup: This is the actual composition phase where users utilize a dedicated and easy-to-use mashup development tool for mashing up the recommended and required components, as defined in the previous phase. Here users are able to drag-and-drop the components and interactively configure and customize the components' layout according to their personal taste and preferences. In this phase, support with regard to clarifying the components and services to users is basically essential and therefore those actors who provide information and/or intangible values to users should be involved throughout the composition process. With regard to patients, healthcaregivers and healthcare providers are the ones who are required to directly assist the patients during the process. In order to make the environment more adaptable to users and improve its value, users can be provided with a set of similar and dissimilar components in order to be able to substitute them on an as-needed basis (Germonprez et al. 2007), and by this, users integrate specific and reusable components in order to create a unique healthcare environment. As Pask argues (Pask 1971), users may enjoy this process due to the fact that the environment and the technologies, which they are using and configuring, are being designed to support their needs and requirements; therefore they are achieving their goals through technology. In order to streamline the mashup composition process for users, easy and simple exploration, organization, and integration of components or services should be provided (Yu et al. 2008), and therefore different Web 2.0 technologies are being easily combined to enhance the mashup capability (Cheung, Yip et al. 2008).

Content Production: As a result of the previous phase, each user has a personalized environment where the preliminary components have already been integrated, and in this phase information is being tailored to users, based on their defined particular needs and preferences, through multiple content providers and diverse data sources, as shown in the Figure 2. In this phase, users either work with existing content or create and manage their own content; and users may create content individually or in collaboration with other actors. For example, patients with chronic diseases receive news, articles, and information about their condition from data sources of their choice, or from their healthcaregivers; or personalized information, articles, or advice related to patients' condition are generated by correlating information from patients' health records in order to inform patients or healthcaregivers (Karkalis & Koutsouris 2006). Various pieces of information, such as discussions, chat histories, images, documents or files, are being produced in this phase, but there is a requirement that all this information is provided in a way that allows users to determine its credibility and validity with full transparency regarding the source of the content. Therefore effective procedures and contribution policies should be in place in order improve the quality of provided information and knowledge sharing (Wright et al. 2009).

User Experience Analysis and Evaluation: In this phase, users' experiences of the healthcare environment together with different aspects of the system are analyzed and evaluated. The aim of this phase is to realize whether the fundamental users' needs and values are supported by the system (Väänänen-Vainio-Mattila et al. 2008), and therefore user experience should be a key concern here in order to refine the iterative development process. In this phase, all the actors of the healthcare process should be involved in order to reflect different perspectives and opinions on each others' experiences, and also to check whether their experiences match their original goals and needs. In addition, the functionality of integrated components and the level of user engagement should be evaluated adequately. The WebMedQual guideline for website assessment contains constructs for the assessment of information content, the authority of source, accessibility, links, user support and privacy (Provost et al. 2006), which can be used a tool for further analysis and evaluation of the developed environment. Based on the outcomes of the evaluation and users' feedback, effective methods should be applied in order to revise and develop the users' needs and to better proceed with the iterative process. It is important here to let the users establish, prioritize and verify the requirements (Boehm & Turner 2003) and rely on their knowledge for capturing and documenting the new requirements.

We believe that by following the above iterative user-centered approach, great improvements to the development of our proposed framework will be achieved and important issues and new ideas may arise which could be considered throughout the iterative process.

6. CONCLUSION

Patient-centered healthcare models are emerging rapidly and they are shaping a positive future for health and healthcare. In this paper we proposed a framework to create a healthcare environment through mashup technology in order to implement the main goals of patient centered models. We believe that mashup technology is able to support users' engagement significantly by providing them with sufficient variety and flexibility where users are able to actively describe and modify their own environment; therefore mashups can be considered as an adequate foundation for implementing our proposed framework.

As mentioned before, our proposed framework targets all the actors of the healthcare process and not just patients. For this reason there should be multiple implementations of the framework in order to accommodate the needs of each actor. This motivates using an iterative user-centered development process which is highly recommended.

Validation of our proposed framework is in progress where we are using different mashup tools like "Joomla!" (Open Source Matters Inc. 2010) as a high-level and module-based web-based software, and MashMaker as an interactive tool which allows non-expert users to easily create their own mashups based on data and queries produced by other users and by remote sites (Ennals & Garofalakis 2007). Future research work will involve the evaluation of the proposed framework in different healthcare settings and the refinement of its development process. Therefore, the next steps will involve testing the framework in various case studies and healthcare scenarios which will lead to a comprehensive evaluation of our proposed framework.

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