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Patient-oriented Design of Online Support Communities

Jan Marco Leimeister, Helmut Krömer

*Information Systems (I17), Technische Universität München
Boltzmannstr.3, 85748 Garching, Germany
{leimeister; krcmar}@in.tum.de*

Abstract

This paper focuses on the process of designing and implementing an online support community for patients. After an introduction we describe a process for translating the socio-technical needs of cancer patients into system requirements as well as the development steps towards a functioning community platform for cancer patients. We combine a generic iterative process model for systems development with a prototyping approach towards an engineering process model for community platforms for cancer patients. We focus on specialties and challenges during the system development concerning user interface development and system requirements' analysis. The objective is to derive a model for developing community platforms that has a proven track of being applicable during system development

1 Introduction¹

Community platforms on the Internet have great potentials to serve ubiquitous information and interaction needs. Such an omnipresent demand exists for instance in healthcare, when patients develop a desire for information and communication possibilities exceeding the offers of the treating physician.

Patients' needs and demands for information often increase after a diagnosis of a disease or during medical treatment (Sheppherd, et al., 1999). Patients may seek information to help them making sense of a cancer diagnosis or in making decisions about treatment. Besides demands for factual information, there can be a desire to seek emotional support and to communicate with other patients. These behaviours play an important role in dealing emotionally with a disease, an assumption backed by research on self help groups (for an overview see e.g. (Hasebrook, 1993)). The complexity of treatment modalities coupled with hardly manageable professional and lay literature in this area makes coping with the informational, emotional and medical aspects of life-threatening diseases extremely difficult, even through participation in (virtual) communities.

Designing and building virtual communities has been in the focus of science and practice for a couple of years (for an overview see e.g. (Schoberth and Schrott, 2001)). However there are hardly any empirically tested process models for the development of community platforms in general and even less in the healthcare sector. In the following we will indicate our first steps towards creating a process model for developing community platforms in healthcare.

2 Requirements and the Development Process

2.1 The Problems of Requirements Collection

Although software development is usually done within an organizational framework, many of the developed information systems do not match the needs of the target users. Many orphaned community platforms on the internet underline this. Traditionally system development takes place in a linear manner, starting with the conception phase and ending with the phase of the death or substitution of the system. Many alternative models have been developed since the linear model holds many dysfunctional aspects (see (Boehm, 1988)). The internet as a possible environment for an information system, especially with its heterogeneous user groups, demands more flexibility and has a high degree of uncertainty concerning how hardware and software will be used.

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The collection of requirements often takes place very early in the development process and is transferred into a requirements specification. Little attention is paid to the alteration or adaptation of already acquired requirements during the following phases. There is little time and space to pick up on new requirements in most processes. Mistakes within the requirements specification and the management of customer requirements reduce system quality and generate high costs for ongoing system corrections.

Therefore the collection of requirements should be emphasized and the target user should be involved in early stages of the software development cycle. The requirements engineering approach tries to fulfil this request. Requirements engineering is defined by the IEEE Std. 610.12 as “(1) the process of studying user needs to arrive at a definition of [...] requirements; and (2) the process of studying and refining [...] requirements” (1990, cited in (Hoffmann, 2000)). It also emphasizes the fact that requirements can change during the development process. In order to develop a platform that meets users’ needs, requirements engineering addresses many essential success factors for system development and is therefore a suitable framework for the development of a community platform in general. There are many activities and methods reported in the literature that guide and support the discovery of requirements (for an overview see (Hoffmann, 2000)), but are they applicable for our purpose and can they be combined with a process model for system development?

Although considering many published approaches², we did not find an appropriate model that combined both an applicable process for the development of a platform on the internet and the inclusion of requirements engineering activities that involve intense participation of targeted users, and certainly none with a proven track record.

2.2 Requirements for the Development of a Community for Cancer Patients

In the following we will focus on the development of an online support community for cancer patients. In order to identify information and interaction needs of cancer patients we conducted field studies (see e.g. (Leimeister, et al., 2002)) and their results lead to the general requirements for a process model listed in Table 1 .

Results/ Section	General requirements for a community platform for cancer patients	Implications for a process model
<i>Development of platform</i>	The envisioned community platform is an <i>innovation</i> . No comparable system exists on the German speaking internet (none offers interaction possibilities). Therefore all the <i>requirements cannot be collected in advance</i> or copied from existing platforms; moreover they appear and change during the development process. Activities should be ongoing throughout the development to collect and evaluate requirements. The future environment of the system, the Internet itself, opposes <i>a flexible design of the front end</i> . Aspects such as size of screen, supported types of browsers and transfer rates must be taken into consideration within the development process. The targeted users, patients are often not familiar with the use of the internet or information systems in general and therefore are not able to transfer their needs into a concrete design of web site services. The development must involve representatives for the target users (for similar findings see e.g. (Forsythe, 1992)). Groups of experts for example can function as representatives at the very beginning of the development cycle until there is something tangible, like a demonstration prototype which can be presented to the patients for evaluation.	Iterative process necessary; high degree of user involvement necessary; use of prototypes for demonstration purposes and testing on the internet is necessary.

² Process models for the development of community platforms in general can either be derived from existing information system development approaches (for an overview see Boehm, B.W. "A spiral model of software development and enhancement," *Computer* (21:5), 1988, pp. 61-72.) or from community informatics works with a rather social science perspective on community (platform) building such as Preece (2000) or Kim (1999). But none of the existing approaches seems to be appropriate since they are either not detailed or feasible enough or too extensive for being manageable for smaller projects. The development of information and interaction platforms for patients in general or cancer patients in particular has special requirements that are hard to integrate in existing process models for system development.

Results/Section	General requirements for a community platform for cancer patients	Implications for a process model
Target group	The <i>navigation</i> of the platform should be <i>intuitive</i> as most cancer patients are older and unfamiliar with the use of the internet (for similar findings see e.g. (Binsted, et al., 1995)). The use of colours, a constant navigation bar, larger font size and the <i>avoidance of fancy features</i> (flash-animations, mouse-over, etc) is advisable. Trust is a crucial element for target group, therefore access-right structures that support the development of trust and that support real-life situations and interactions are necessary (Leimeister, et al., 2005)	Use of mock-ups and prototypes for demonstration purposes is necessary; process has to include access-right structures development; process must adapt to changes of requirements during development.
Content for platform	The platform should have an <i>information section</i> as well as <i>interaction possibilities</i> . The offered <i>information must be trustworthy and comprehensible</i> for patients.	Development process should be applicable for different types of services (information and interaction services).

Table 1: Deducted requirements from field studies (Arnold, et al., 2003)

Starting with these first requirements, a process model for engineering patient support communities has to allow the integration of parallel activities of requirements engineering in order to provide the flexibility needed for the development of a platform for cancer patients on the Internet. Therefore an applicable process model should: be an iterative process, be able to adapt to changes of requirements during the development process, include several builds of prototypes, be easy to apply especially for small and medium size projects, be applicable for different types of services (information as well as interaction), and involve users and/or experts from the beginning. The following suggests a process model that meets these preconditions.

2.3 A Community Platform Engineering Process (COPEP)

The objective of this section is to describe a process model for developing an information system, a community platform for cancer patients. Since system requirements are neither completely nor exactly defined, a linear model does not fit the uncertainty that arises from the field. An iterative model seems to be more appropriate. Starting out with general requirements, the system can be built step by step. The outcome of each stage of the iterative development should be evaluated. Within each iteration, however, the type of development should be shaped by the demands of the situation. Figure 1 shows the process model COPEP (Community Platform Engineering Process) that was used during the development of the Internet platform www.krebsgemeinschaft.de for the target group of breast cancer patients.

The heart of this model is an iterative process, adapted from the generic spiral process model (Boehm, 1988; Wigand, et al., 1998). It is combined with a prototyping approach. Each iteration consists of four phases: planning, analysis, engineering and evaluation. Different from the original spiral model, a much stronger focus has to be put on the building of prototypes and the involvement of users in evaluation. The goal of the engineering phase of each iteration is the building of a prototype in order to get a tangible version of parts or the whole product very early in the development process. After the evaluation phase, the second iteration starts over with planning again, but applying experiences from the previous iteration.

As Figure 1 shows, each prototype undergoes an evaluation at the end of its development cycle. That allows a high degree of involvement of target users, with experts as their representatives. The method used for evaluation was a mixture of interviews and group discussions. We presented the results of each cycle to a group of experts (iteration 1 to 3) and to a group of patients (iteration 4 and during the run of the prototype). Their feedback was integrated into the planning of the next iteration. The prototype was introduced to a broader public on August 18th 2002.

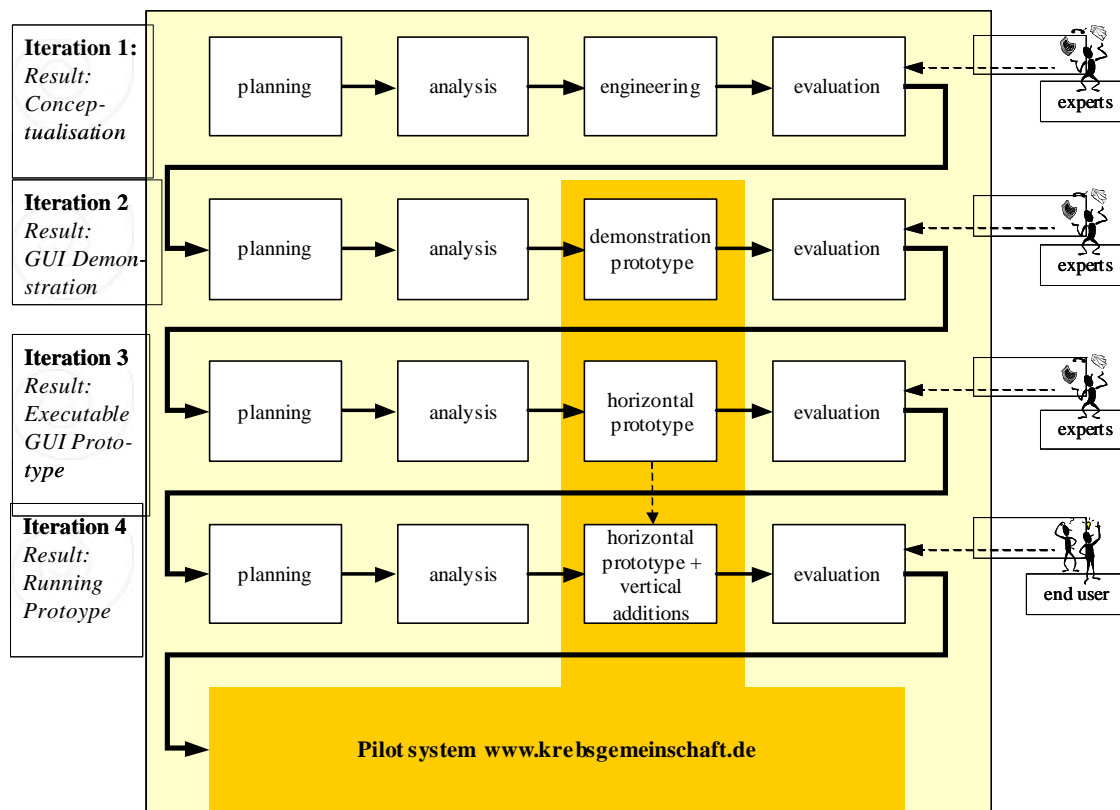


Figure 1: Community Platform Engineering Process with 4 Iterations combining a spiral model with prototyping elements (shaded)

Through an early involvement of various stakeholders in the development cycle and the visualization of parts of the end product through prototyping, COPEP counters the danger of dragging inappropriate requirements, fixed in the beginning, into the end product. General requirements get more detailed as the development process goes on, and mistakes made in the beginning can be redefined.

3 Design of an Online Platform for Cancer Patients

3.1 Socio-technical System Design

A socio-technical design for virtual healthcare communities has to consider (among others) the following issues for being successful (see also (Leimeister, et al., 2002)):

- Creation of a virtual information and interaction space with appropriate communication channels according to cancer patients needs.
- Trustworthy operators (no financial interest in the subject, explicit competence in medical issues, etc.) of the community platform and transparency about the source of funds in order to support the development of trust.
- Competent content managers for the quality assurance of centrally provided content.
- Access-right structures that support the development of trust and that also support real-life situations and interactions.
- The provision of tools for working with shared material for supporting group activities that have been successfully used in computer-supported meetings for a longer time (Nunamaker, et al., 1997).
- The facility for an active community-management to remotely monitor and control the participants' information and interaction spaces and the tools within the system (an equivalent for the role of a self help group leader in order to avoid problems known from real-life groups like charlatanism, etc.).

Cancer patients are migrating between different contexts, such as different hospitals and medical centres, work and home. Hospitals or medical professionals remain their most important source of information (Kaminski, et al., 2001), but information and interaction desires are ubiquitous and don't stick to office hours of physicians. Besides that there are other needs than just medical knowledge retrieval. The desire for social peer-to-peer interaction, emotional support is independent of time, cost or stage of disease and mobility and also of structures required by self-help groups (Hasebrook, 1993). Opening oneself to others, dealing with very intimate and private issues requires an intimate environment. Trust could be, as always, identified as a very critical issue.

We suggest (in accordance with (Gryczan and Züllighoven, 1992)) to provide useful digital tools and digital materials for cancer patients. Tools allow modification and processing of material. In tradition of Computer Supported Collaborative Work (CSCW), tools can enable users to communicate, to coordinate common tasks or to cooperate at shared material (Krcmar and Klein, 2001). Trust-related issues can be approached through a high priority of data-security and a highly specialised and scalable authorisation concept.

Therefore we propose an approach using the room-metaphor for software design (for details see also (Schwabe and Krcmar, 2000)). Its advantages -from the point of view of software engineering- lie in several aspects: It allows an intuitive handling of documents, easy-to-adopt access right structures and supports existing ways of cooperation and coordination in social structures (Schwabe and Krcmar, 2000).

Following types of information- and interaction spaces seem to be useful for cancer patients: A "*private room*", where the user can store private information, documents, links, and have direct communication with others only after having them invited to join; a "*public room*", where all members and visitors of the virtual community can see all information and documents and search for information; a "*group room*", which is restricted to members of a group (e. g. like the self help groups) and provides to all group members access to all documents in this group room and all group related issues.

This is especially backed through the results of our ethnographic studies of self help groups, where almost all active members stated strong interest in maintaining their used social group structures combined with the wish for unrestricted access to information and spontaneous interaction with others.

3.2 Applying COPEP: Iterative Development of www.krebsgemeinschaft.de as an Example for Online Support Communities

In the following we are giving an extract of the development steps during each iteration with a focus on the findings from the concluding group discussions either with patients or with experts (for further details see (Arnold, et al., 2003)).

User Involvement - COPEP counters the danger of fixating incorrect requirements during the initial phases of development by involving end users early on in the development cycle. Visualization of parts of the end product through mock-ups, scenario discussion and prototyping induce a high level of transparency. General requirements get more detailed as the development process progresses and mistakes can be redefined. The targeted users, in our case breast cancer patients, are often unfamiliar with the use of the internet or information systems in general. The proposed community platform was somewhat difficult for them to envision. It was also difficult for them to transfer their needs into a concrete design of a web site from scratch. Further, their fragile medical state prohibited prolonged and unrestricted access to them as collaborative partners. In order to meet the substantial claim of user involvement from the very beginning, representatives for the target users were substituted as consultants for the project (for similar findings see e.g. (Forsythe, 1992)). The role of target group representatives is to take up various positions upon the system until there are mock-ups or prototypes functioning as visualization that can be presented to the intended end users. We used a group of various stakeholders as representatives in order to work with as many perspectives on the system as possible. Once the content for the platform is roughly outlined and the case scenarios are conceptualised (in our case at the end of the third iteration) the target users can more easily get involved. At this point in development, the target users are confronted with the intermediate result as a basis for further design, adaptation and detailing.

Results of the first Iteration - Going from the general requirements we designed a draft what kind of services the platform should contain. For the categorization we used the suggested composition by Brunold et al. (2000). They work with four main sections: information, communication, participation and orientation category. As seen above, the orientation category is very important since the target group is not so familiar with the use of the internet. The concept (see Figure 2) was approved in the discussion by the experts. Possible services that match the needs of the patients were collected in a brainstorming. Moreover the evaluation lead to the requirement that the platform has to

be divided into a public and a private space in order to protect users of the platform from anonymous invasion. Especially the interaction and participation services should only be usable after a previous registration and login.

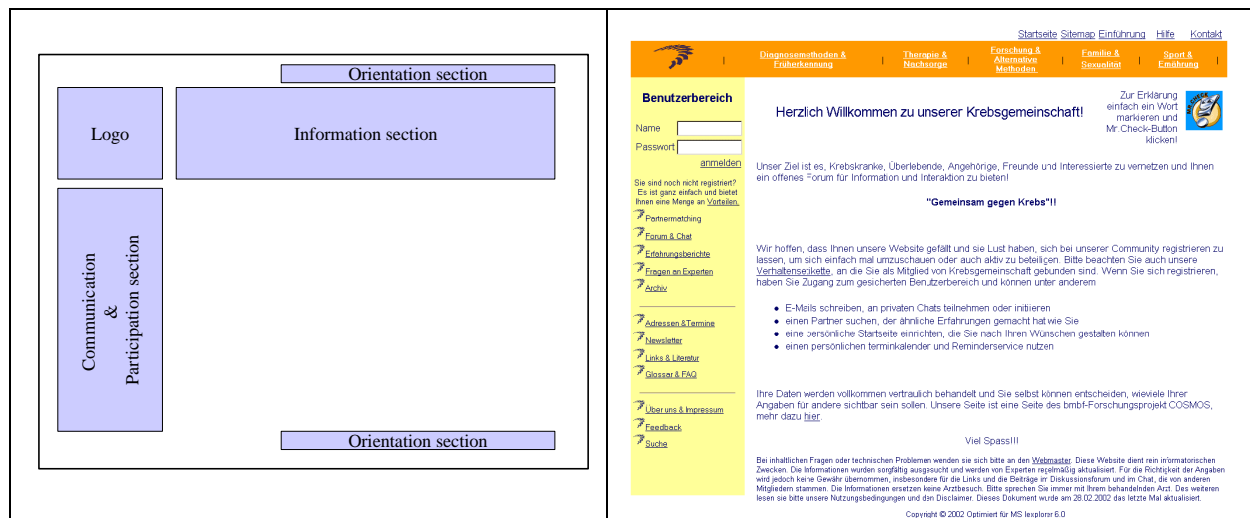


Figure 2: Division into sections & Demonstration Prototype (Arnold, et al., 2003)

Results of the second Iteration - The work in the second iteration focuses on the design of the front end. It is made tangible for evaluation with the help of a demonstration prototype (see Figure 3). Furthermore the information section is planned in further details and the colour spectrum is determined: orange, yellow and white should mediate warmth, brightness, optimism and hope.

According to the reading habits of web user and the distribution of attention on web sites, subcategories within the sections are placed. An evaluation by experts lead to the result that some services were put into different categories and aspects that seem to be more important are placed accordingly (for example: soft facts like sport and cancer, nutrition tips are summarized in a new subcategory 'how to deal with cancer').

Results of the third iteration - The third iteration focuses on vertical supplements of the demonstration prototype. A map showing what pages are linked is the base for further development. Furthermore the communication and participation section is planned in further details. The evaluation at the end of the third iteration produce only little new aspects which shows us, that it is time to go a step further and present the system to real users.

Results of the fourth iteration

At the end of the **fourth iteration** a run able prototype exists that is shown to end user, a group of patients who have only little knowledge of the use of the internet. At the beginning the users kind of disassociate from the system because of their suspicion against the internet in general. Throughout the discussion they get excited about the system and had only little to complain about. We implemented their impulses like to stress certain categories which are more important than others (emphasizing the tip in iteration two from the experts).

Going live

In conclusion a prototype for the target group breast cancer patients was introduced to a broader public on August 18th 2002. At present, there are approximately 1300 registered users on the platform for breast cancer patients with new registrations daily. Accompanying the continual refinement of the platform, an evaluation of the running platform is conducted, taking into account click streams, typical behaviour of heavy users, content analysis of the entries of the personal guest books as well as a collection of feedback to the design of the platform via email, user surveys and group discussions with cancer patients.

The feedback of the users about the design of the navigation and the structure of the breast cancer community was very positive (for additional details on the evaluation of the platform see also (Leimeister, 2004; Leimeister, et al., 2005). Therefore a second platform – for the target group leukaemia patients –was structured and designed the same way. Only the information area has been changed because of the higher variety of diseases within leukaemia. This Internet community was introduced to a broader public on May 21st 2003.

3.3 Separation into Different Areas for Providing Transparency

It is of great importance in the healthcare field to identify and segregate scientific and user generated content. Patients are probably not aware of the difference between facts and opinions. This has legal consequences with respect to liability issues as well as to quality assurance issues of user generated content. A possible solution for the problem of separation between centrally provided and quality assured content and user generated content is to emphasise the difference through design – here made possible with the use of tabs at the top of the page (all centrally provided content is found here in the horizontal “content bar”) and marking all the user generated content (mostly found under on the vertical “functionality bar”) throughout the page with a disclaimer (see Figure 3). This should provide transparency as to the source of the information.

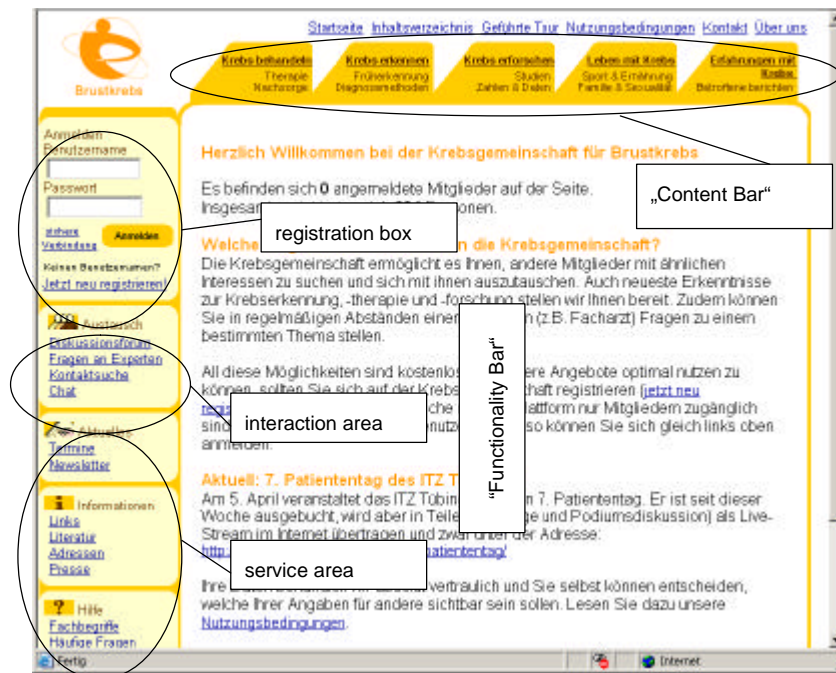


Figure 3: Starting page of <http://brustkrebs.krebsgemeinschaft.de> – a platform for breast cancer patients

User can only communicate or generate content as long as they are logged on to the platform. The first registration process is standardised and should guarantee, that the identity of prospective users is double-checked before allowing new users access to all functionalities. Taking usability aspects into consideration another reason for segregation of content and functionality comes into play: Usability of websites is considered better when content (“content bar”) and functionalities – here aggregated to an interaction area (“functionality bar”) – are located on different areas of the page. Components that provide the possibility of communication with each other are placed on the left of the screen within the interaction area. This area is only accessible after registration.

3.4 Private Space and Personalisation

Parts of a private room as stated in sect. 3 are realised within the individual welcome page. This page is only visible to the user after login (see Figure 4).

There the user has access to his personal mailbox; he can modify his personal data and decide which part of the data should be visible to other community members. Beyond he can create a list of friends (buddy list) who have access to more of his data than the rest of the community.

The possibility to give individual recommendations to other users of the community completes the service of the ‘private’ room. Recommendations could be links to other interesting web sites, addresses of good clinics, helpful literature or references to related events.



Figure 4: The Personal Page of <http://www.leukaemie.krebsgemeinschaft.de> – a platform for leukaemia patients

3.5 Outlook for krebsgemeinschaft.de - Notifications and Rating possibilities

In order to encourage a more lively community and to intensify the integration of user generated content there are several components projected: the buddy list will be extended by a notification tool. Each time a user logs on or does a certain action on the platform, his buddies get a message.

Another projected component is the possibility that the scientific content should be rateable by users. They will be able to comment the user generated content as well as the centrally provided content in order to give each other or new users an orientation.

4 Adding Value to Online Communities through Mobile Services

Another promising area for the extension and improvement of virtual communities is the sector of mobile devices and mobile services. They can add value to traditional web-based communities for several reasons. They extend and/or improve already existing services. Through ubiquitous access to already existing web-based offers community members have all services at any time and at any place. That means that community members have the possibility to inform themselves and to interact with others at any place and at any time. They are no longer bound to their personal computers at home or at work. The second point concerns secure and easy user authentication. Users of mobile devices normally carry their device with them and their device is technically easy to identify (e.g. via the SIM-Card and/or the device ID). This and a personal PIN allows for easy and feasible possibilities for user identification (e.g. automated log-in procedures, etc.). Another improvement concerns already existing reminder services on the Internet. SMS-based reminder services, for instance for the next medical examination or especially for drugs/pills are by far more efficient. Most devices are “always on” and close to the user, therefore the reminder reaches its addressee more often and better in contrast to a mailbox on the Internet.

The other class of advantages refers to new services enabled through the new possibilities mobile devices. These devices support context sensitive and location based services. That means for instance awareness services of who (buddy) or what (location) is around. These services can be push or pull services. Push service means that information is offered by the mobile device that a certain person/location is nearby. If it is a pull service the user has to start a request to get the information he wants. Furthermore it is possible to choose context and location attributes

for selecting contacts, for example spontaneous matchmaking. Of course the user can specify rules and parameters like when, how and for whom they want to be reachable. Other new services in the medical field are emergency services. It is possible to monitor parameters like blood pressure, pulse rate, temperature or electrocardiograms. They can be transmitted to a service centre or to a physician. If necessary (life-threatening parameters) an emergency call can be generated automatically and through the location/positioning service the patient can be found easily. Another kind of new mobile services deals with transaction support. Micro-payment means the possibility to pay via a mobile device, but there are many more possible applications to come. Which services might be valuable to cancer patients in general and to members of a cancer patient community in particular has to be investigated yet. With the COSMOS-project we hope to clarify some of the issues concerning mobile services for cancer patients.

5 Summary and Outlook

Virtual communities are a very promising approach for patients for overcoming information asymmetries and for supporting interaction. Especially for cancer patients it seems to be a very promising model, since cancer patients have strong and ubiquitous demands for valid and trustworthy information and intensive wishes for empathy and interaction with other peers in similar situations. We outlined how a systematic design of a virtual community for cancer patients in Germany can be achieved. On the basis of in-depth field studies and with the application of an iterative development process, we have shown how requirements for community engineering and system development in this domain look like and what kind of components can be useful for a virtual community for patients. Mobile services have the potential to add significant value to virtual communities and especially the aspects of ubiquitous access to a community and its members and new services enabled through new mobile technologies seems very promising.

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