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ENGINEERING VIRTUAL COMMUNITIES IN HEALTHCARE: -THE CASE OF WWW.KREBSGEMEINSCHAFT.DE

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ABSTRACT

Virtual communities can –theoretically- be described as a solution for meeting ubiquitous information and interaction needs. Such needs occur in healthcare, when for example freshly diagnosed cancer patients develop very strong information and interaction needs. But how can such a platform for cancer patients be designed, implemented and introduced practically? Investigating this lies at the heart of the COSMOS¹-Project, parent project of the site www.krebsgemeinschaft.de. In order to understand cancer patients' situation we have conducted several field studies and have identified information and interaction needs. On this basis we have derived requirements for user centric socio technical system design for cancer patients. Since no existing offers in the European/non-English-speaking internet have met these prerequisites we have started to develop and implement a virtual community for cancer patients. Hereby two topics are of special interest. First, how to systematically plan a community platform for this target group or in other words how a process model for the development and the introduction should look like and second, what specifications a possible technical infrastructure has to meet. For the future subjects like ubiquitous community access, new possibilities of user identification and location related services are also of special interest since they might allow real anytime-anyplace access to the community platform or new, value-adding services to community members. But nevertheless: Only socially accepted, technically stable and economically feasible solutions can ensure sustainable success of (mobile) virtual healthcare communities.

¹ This paper resulted from the research project COSMOS (Community Online Services and Mobile Solutions) COSMOS is a joint research project of the Hohenheim University, the Technical University Munich, Ericsson Deutschland GmbH and O₂ (Viag Interkom GmbH & Co). The project is funded by the German Ministry of Research and Education under contract No FKZ 01 HW 0107 - 01 HW 0110. For further information please visit the website: <http://www.cosmos-community.org>.

1 INTRODUCTION

Virtual Communities (VC) can be defined as a group of people who gather because of a common interest, problem or task and whose members are independent of time and space for interacting (Klein/Leimeister/Krcmar 2001); (Leimeister/Daum/Krcmar 2002), for similar definitions see also (Armstrong/Hagel III 1996; Mynatt et al. 1997; Preece 2000; Schubert 1999). Virtual Communities provide ubiquitous information and interaction spaces. For being accessible and usable at any time and from any place, information and communication technology (ICT) is a crucial element.

Virtual communities have great potentials to serve ubiquitous needs. Such an omnipresent problem situation exists for instance in healthcare, when patients develop a desire for information and communication exceeding the offers of the treating physician. From the characterisation of virtual healthcare communities as ubiquitous information and interaction spaces we derive design requirements for VCs as well as for the process of developing a community platform. The results are transferred into the healthcare domain, particularly into the situation of cancer patients. On this basis we give an overview of our experiences with the development of a community platform for breast cancer patients. In closing we put special emphasis is put on the possibilities and challenges of mobile technologies for virtual healthcare communities. The objective of this work is to research the planning and building of a virtual community for cancer patients in a real life setting under special consideration of the new possibilities of mobile technologies and mobile services.

2 RESEARCH DESIGN

Research design describes the key objectives of the research project, what methods will be used for data collection and analysis as well as how the research process shall take place. The objective of this venture is to plan, build, introduce and evaluate IS-platforms for cancer patients. Pilot projects are a special version of interventionistic science. They develop and implement technological innovations in their natural organisational and social environment (Schwabe/Krcmar 2000b).

Starting-point of pilot projects is usually a socio-organisational problem (in this case the situation of cancer patients after they leave hospital). At the beginning an analysis of cancer patients situations' is performed in depth through literature review and above all case studies, using interviews, questionnaires, observations and document analyses (Yin 1989). The results of the analysis are used for designing an IS-platform. This platform is implemented in the field and finally improvements in the system are made during the remainder of the project. At all times, on all levels a continuous evaluation has to take place and thus iterative learning steps of the system developer can be augmented at all stages.

The objective of the field studies was to study cancer patients' needs and to analyse already available web-based offers for cancer patients. Therefore we analysed the situation of cancer patients in general with a standardised questionnaire, followed by in depth studies in 5 different cancer self help groups with approximately 100 active members. We applied for this ethnographic analysis semi-structured interviews, observations and document analysis. After that web-based information and interaction offers were investigated. Finally identified cancer patients' needs and already available offers were compared.

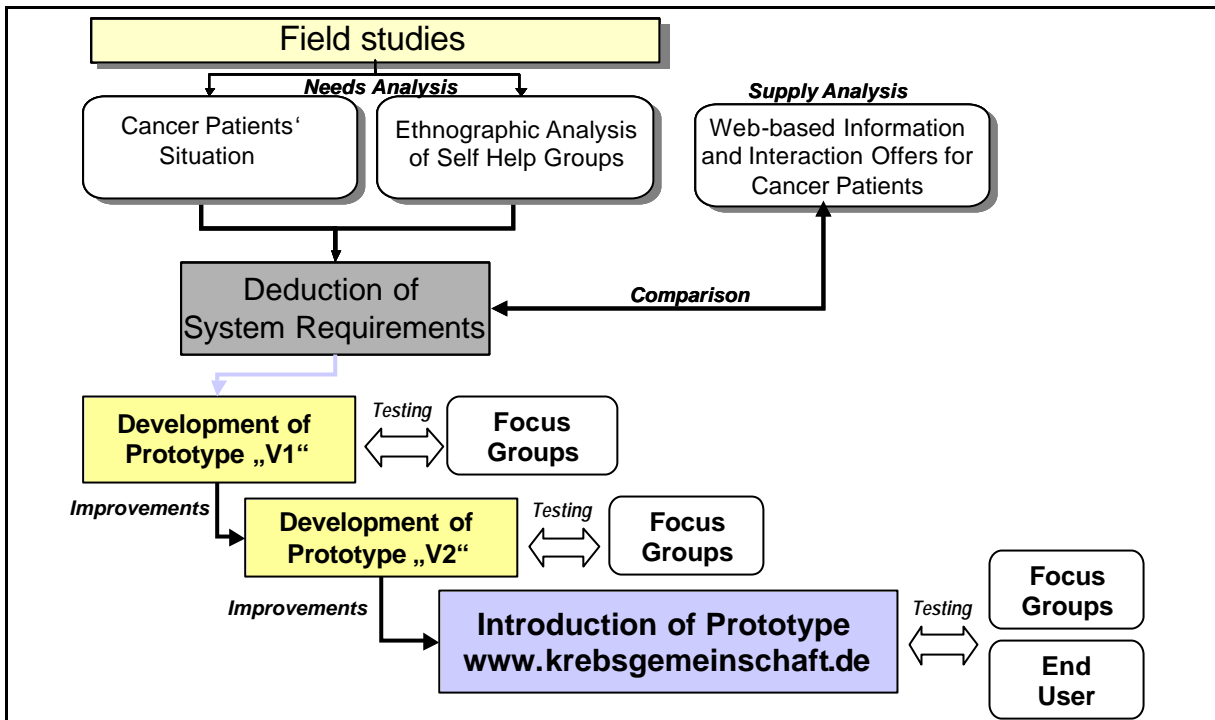


Figure 1: Research Plan

On this basis the development of the prototype began. For the development an iterative process model was chosen in order to allow a high degree of user involvement in the development process. After several iterations the prototype was introduced to public on August 18th 2002. The platform is being tested continuously by users and additionally by focus groups in controlled settings.

3 FINDINGS OF THE NEEDS ANALYSIS

3.1 Needs Analysis of Cancer Patients

Patients' needs and demands for information often increase after a diagnosis of a disease or during medical treatment (Shepherd/Charmock/Gann 1999). These demands can be the result of asymmetric information for instance between patients and physicians. Patients may seek information to help them make sense of a cancer diagnosis or to provide them with information which assists them in making informed 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 can 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)). If we assume, that there is a correlation between the threat to quality of life imposed by a cancer diagnosis and the need to seek and obtain knowledge and support (like e.g. (Eysenbach 2000)), the potential benefit of cancer-related communities becomes evident. However, the diversity of the over 100 types of cancer, the diversity of the presentation of the same disease in two patients, the complexity of treatment modalities coupled with the hardly manageable extensive professional and lay literature in this area combine to make coping with cancer, even through participation in virtual communities, extremely difficult.

Recent research on cancer patients' informational demands (e. g. (Kaminski et al. 2001)) demonstrates a strong information interest in the following areas:

- 1.) Side effects/how I will feel.

- 2.) Explanation of disease and prognosis.
- 3.) Treatment options and explanations of therapy.
- 4.) Logistical issues (transportation, work, etc.).
- 5.) Lifestyle issues (exercise, diet, sexuality, smoking).
- 6.) Follow up/what happens after therapy finishes.
- 7.) Support or self help groups, alternative medicine.

Above these information demands books of cancer survivors like Lance Armstrong (Armstrong 2001) and their huge success show that cancer patients also have strong desires for emotional support and empathy.

Many of patients' needs to find answers to perceived and real problems as well as informational needs can be solved through self help groups. Self help groups exist in many major cities and for different types of cancer. According to information provided by the AOK, Germany's largest health insurer, only approximately 5-10% of cancer patients take part in self help groups. Reasons for this can be, among others, that interested patients are unable to locate a group in their vicinity or that meeting times of groups don't fit individual patient's schedules. Very often integration into a group plays an important role and in particular fear and mistrust in "strangers" are often experienced. Taking part in self help groups is linked with talking about a very intimate subject like one's disease and presents, therefore, a very uncomfortable situation for most patients.

These circumstances of real-life communities on one hand and the demand for information and interaction on the other show the great potential of virtual healthcare communities as ubiquitous information and interaction spaces for solving these problems. Broad-based and enlightening information showing advantages and disadvantages of alternative treatments as well as infrastructure issues such as where one can obtain what type of treatment is not provided. In order to enable patients to be autonomous in their decision-making, a solid information basis is necessary.

What role information systems in general and virtual communities in particular can play in the provision of information and especially what problems they can solve under these circumstances is the subject of the following section.

3.2 Empirical findings of conducted field studies

During the European Week against Cancer (October 2002) a standardised questionnaire was distributed to approximately 500 visitors, the rate of return was 116 questionnaires. The findings were that more than 60% of the cancer patients agree with the question that their physician has a big information advantage. One third of them agree in parts to the statement that they want to look for information on the internet. 28,8% of the female cancer patients use mobile phone as well as the internet, by men mobiles phones are used by 56,3% and the internet by 43,8%. More than two third agreed in parts that they want to communicate more with other patients. These statements emphasize the need for web-based or mobile information and interaction services.

Additionally we conducted ethnographic analysis of self help groups. Therefore we made narrative interviews with self help group leaders and several semi-structured interviews with the group members. The results showed that there is a lack of information and interaction possibilities for cancer patients and their relatives. The patients want and need information about their specific type of cancer, treatment or hospital. Most of the members of self help groups found it important to share information and to speak with other patients in the same or similar situations. They got hope and encouraged when they saw one of the members recovering. Even if the meetings just took place quarterly, the members

called each other by telephone very often to get advice from others. Some members had a long way to their self help group meetings. This fact shows the importance of the self help group for its members.

The use of materials and tools like mobile phones, personal digital assistants or the internet correlates with the average age of the group and the age of the members. In some groups almost all members had mobile phones and used the internet.

Unrestricted access to valid, understandable and relevant information as well as the possibility to contact other patients of the self help group at any time was considered as very important. But this approach is only possible for members of self help groups and therefore not for the majority of cancer patients. Thus our results confirm cancer patients demands for information and interaction services.

3.3 Analysis of web-based Information and Interaction Offers for Cancer Patients

Until the start of the project (mid 2001) a working virtual community for cancer patients couldn't be identified on a European level (German or English speaking), only in the US we were able to find first approaches towards virtual cancer patient communities (Daum et al. 2001). Concerning mobile services support for access through mobile devices we couldn't identify any offer in the German speaking internet. Therefore a pilot project for developing a community platform for cancer patients was initiated.

4 IMPLICATIONS FOR THE PROTOTYPE DEVELOPMENT

4.1 First steps of socio-technical system design

Our research has shown so far, that a socio-technical design for virtual healthcare communities has to consider (among others) the following issues for being successful (see also (Leimeister/Daum/Krcmar 2002)):

1. Creation of a virtual information and interaction space with appropriate communication channels according to cancer patients needs.
2. 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.
3. Competent content managers for the quality assurance of centrally provided content.
4. Access-right structures, that support the development of trust and that also support real-life situations and interactions.
5. 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).
6. The facility for a 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 the 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 require an intimate environment. Trust could be, as always, identified as a very critical issue.

We suggest (in accordance with (Gryczan/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/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/Krcmar 2000a)). 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/Krcmar 2000a). 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.

4.2 Architecture and System Requirements

In order to fulfil diverse requirements on a community-platform, a client-server-solution is utilized whose architecture consists mostly of three layers (data, application and presentation layer). The layer model is a hierarchical composition of communication services (for further details on layer models see also the ISO/OSI-reference model (as described e.g. in (Hansen/Neumann 2001, 1145 pp)). Each service accesses via defined service access points (SAP) services of lower levels and communicates with peer services via protocols.

This architecture allows a high scaling and flexibility of the system as well as extensions by context-sensitive elements. It also offers the advantage of making a modular structure of the platform possible. Furthermore, different standards as for example Extensible Markup Language/Extensible Stylesheet Language (XML/XSL), Hyper Text Markup Language (HTML), Wireless Markup Language (WML), Java Database Connectivity (JDBC) and Hypertext Transfer Protocol over Secure Socket Layer (HTTPS) are supported by this system, thus permitting a support of any access device using a browser (web-browser, WAP-mobile-browser, etc.).

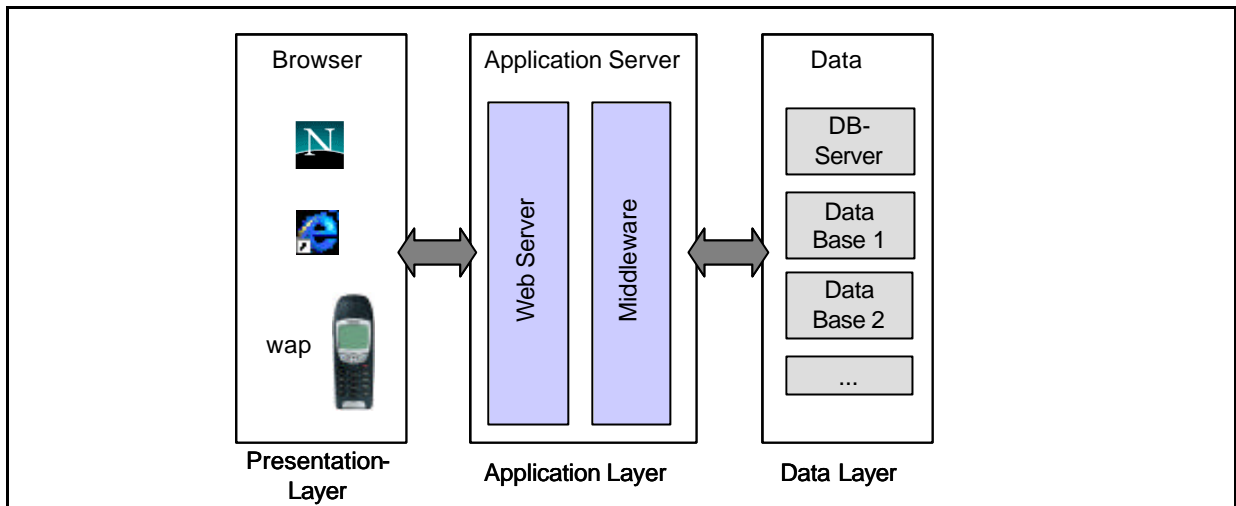


Figure 3: 3-layer-architecture of community-support-systems

The presentation layer regulates the communication between client and server. It is possible to spread it over several computers. Since it carries the major part of the load, systems can be scaled strongly. This layer receives inquiries of users in HTML or WML, converts them in XML and responds in XML-pages, which are again converted into HTML- or WML-pages. The protocol used for communication between the client and the presentation layer, is mostly http but other protocols, in particular WAP as for mobile devices, may also be used.

The application layer responds to inquiries of the presentation layer and takes charge of central functions of the administration. Nearly all the functions of the community are provided on the server-side. Typical functions are for instance calendaring- or chat-modules.

In the data retention layer, information is saved permanently. The system disposes interfaces which are tied up over the data retention systems and which can be applied to the data storage. According to dominant standards, SQL-compatible data bases are supported. In the ideal case, it is irrelevant for the application layer which system is used for the data storage. It accesses structures that are reflected on the respectively available data retention system. Thereby, the application components can be developed independently of the system on which they are based in each case. Thus, for example the integration of existing data sources can be managed.

4.3 A process model for developing a community platform for cancer patients - Towards a Community Platform Engineering Process (CoPEP)

The objective of this section is² to design a process model for developing a community platform for cancer patients. Since system requirements are neither completely nor exactly defined, a linear model does not fit to the uncertainty that arises from the field. An iterative model seems to be more appropriate. Starting out with general requirements, the system can be build step by step. The outcome of each interval of the iterative development should be evaluated periodically. Within each iteration however the type of development should be shaped accordingly to the demands of the situation. Figure 1 shows the process model CoPEP (Community Platform Engineering Process) that was used during the development the platform www.krebsgemeinschaft.de for the target group breast cancer patients.

² For further details on the development of a process model for virtual community platforms see also (Arnold/Leimeister/Krcmar 2003)

The heart of this process model is an iterative process, adapted from the generic spiral process model (Boehm, 1989, 26 and Wigand 1998). It is combined with a prototyping approach. Each iteration consists of four phases: planning, analysis, engineering and evaluation. Differently than in the original spiral model a much stronger focus has to be put on the built of prototypes and the involvement of users for evaluation.

The goal of the engineering phase of each iteration is the built 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 concerning experiences from the previous iteration.

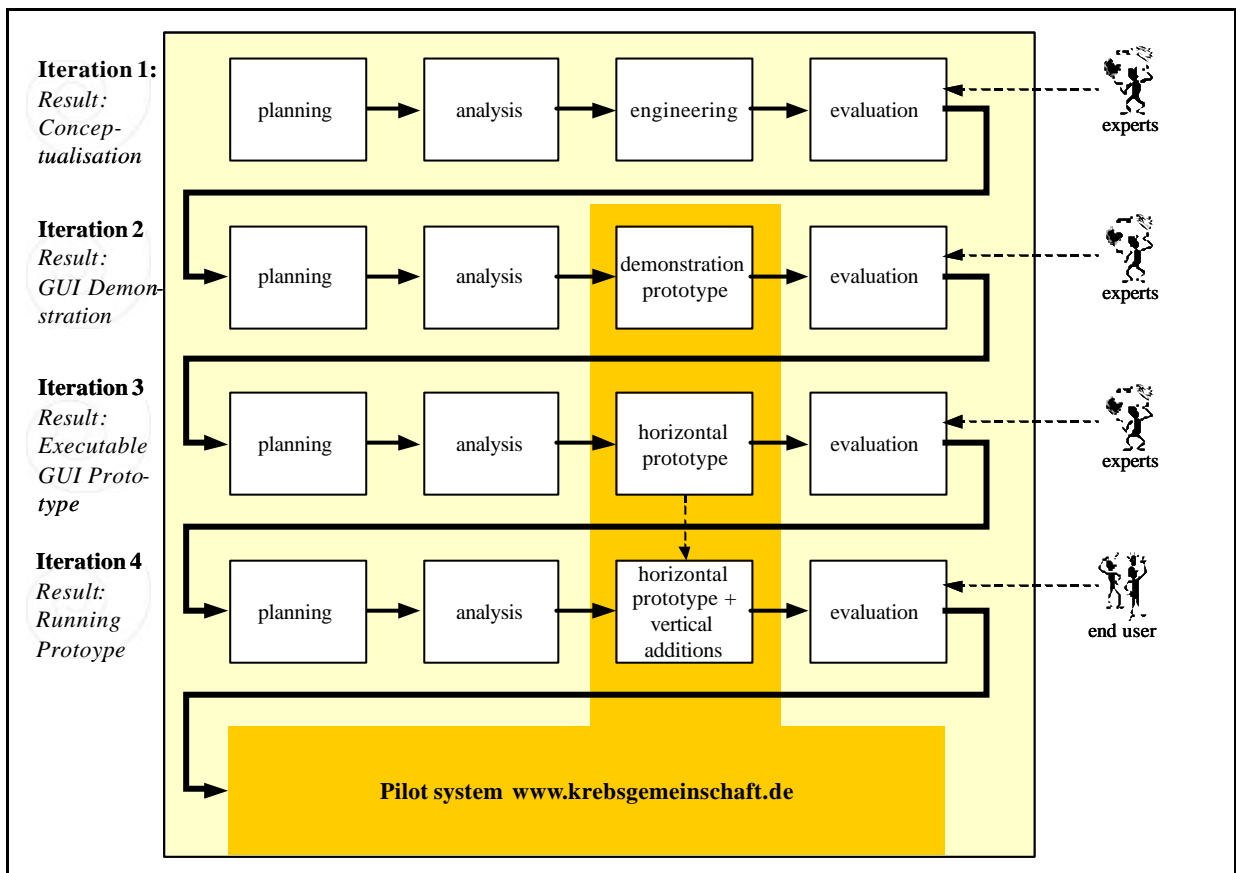


Figure 2: Community Platform Engineering Process with 4 Iterations, combining a spiral model (light yellow) with prototyping (dark yellow) (Arnold/Leimeister/Krcmar 2003)

As figure 2 shows each prototype undergoes an evaluation at the end of its development cycle. That allows a high degree of involvement of target users respectively 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 is integrated into the planning of the next iteration. In conclusion the prototype was introduced to a broader public on August 18th 2002.

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 wrong requirements fixed in the beginning along to the end product. General requirements get more detailed as the development process goes on and mistakes done in the beginning can be redefined.

For the development of a community platform we suggest to use an iterative process model. The access to a representative group of users is very difficult to achieve, since the common criteria 'cancer patient' is a very touchy subject. By distributing questionnaires at patient events or by analysing self help groups we could only address those patients or relatives, who are very active or cope with their disease actively. Since the platform shall serve all cancer patients and relatives we must assume, that many specifications remain unsaid. Since no other similar platform exists in Germany no parallels to other systems could be drawn. Thus a process model is needed, that allows to work with several development iterations without obliging the developer to stick to the same specific process model for each iteration.

Essential to our research has been the involvement of end user testing as often as possible. At the very early stages (for deriving the specifications of our first prototype) we worked with the help of experts who know the target group very well like physicians or social workers. As soon as we could test a first prototype we applied focus groups for evaluation (Krueger 1994) for each iteration in our process model until the going-live of the platform on Aug.18th 2002. Since then we additionally use direct user testing for evaluation and continuous improvement of the system.

4.4 Preliminary results: A web-based prototype for a Community of Breast Cancer Patients in Germany

In conclusion a prototype for the target group breast cancer patients was introduced to a broader public on August 18th 2002 (see Figure 3). By May 03 we have around 700 registered users on the platform with new registrations daily. An evaluation of the running platform is currently carried through taking into account click streams, typical behaviour of heavy users as well as a collection of feedback to the design of the platform. Due to the usage numbers of the platform and the feedback provided from users and experts the platform can be considered successful and thus CoPEP has its first proven track of applicability.

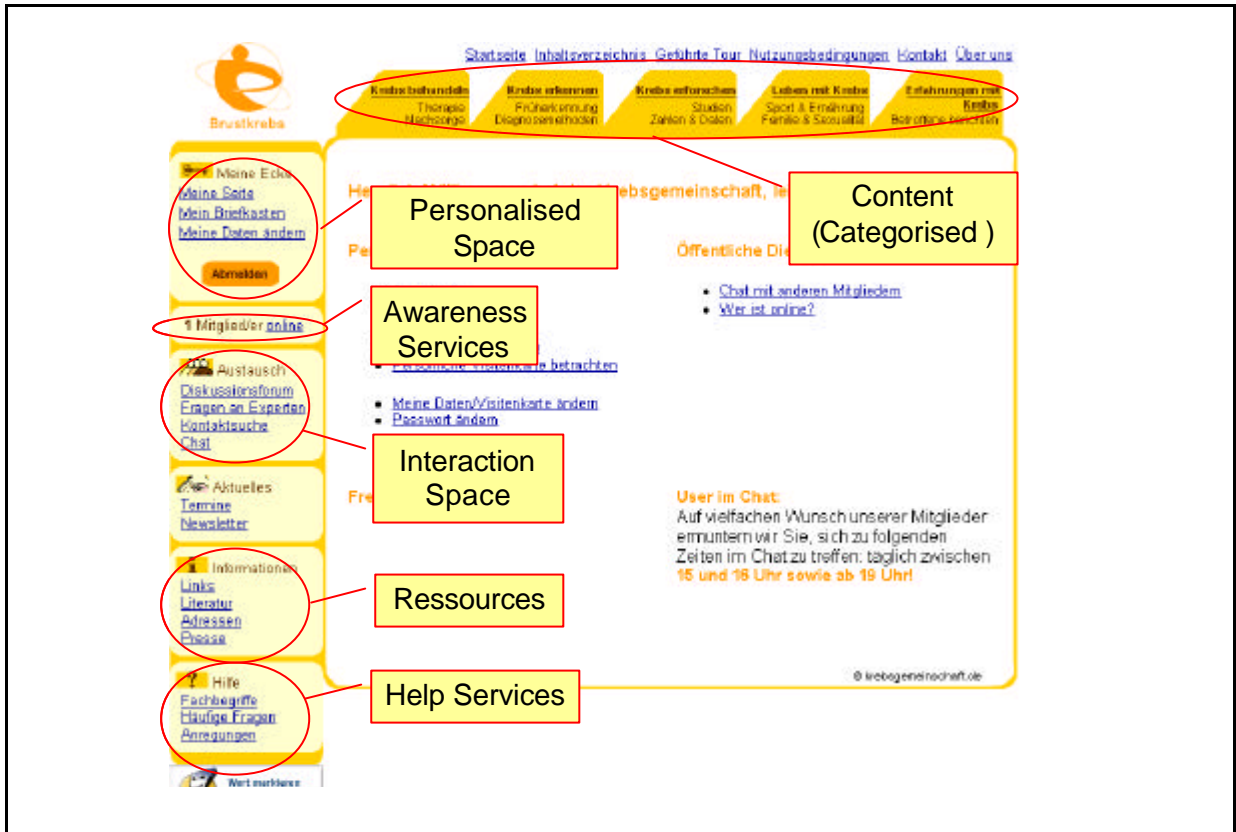


Figure 3: www.krebsgemeinschaft.de, a pilot system for the target group breast cancer patients (Arnold/Leimeister/Krcmar 2003).

5 ADDING VALUE TO VIRTUAL COMMUNITIES THROUGH MOBILE SERVICES

Mobile services can add value to traditional web-based communities for several reasons. They extend and/or improve already existing services. Figure 3 visualises some possibly value-adding services.

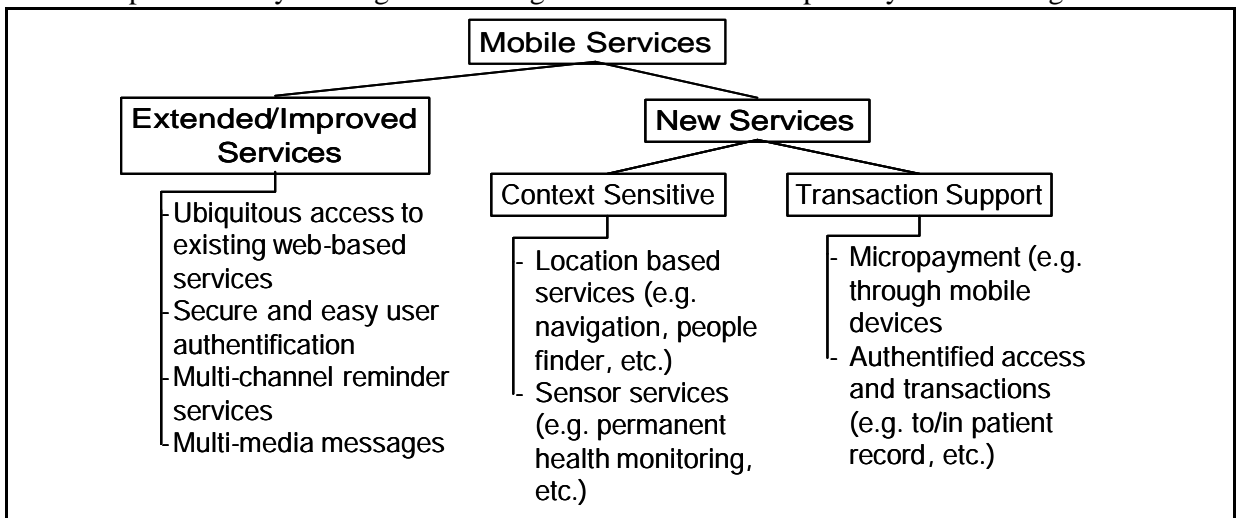


Figure 4: Mobile Services for Adding Value to Virtual Communities.

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. Another new service 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.

6 SUMMARY AND OUTLOOK

Virtual communities are a very promising approach 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 have shown on a basis of in depth field studies, how first requirements for community engineering and system development in this domain has to look like. 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 services and new services enabled through new mobile technologies seems very promising.

Our research has shown so far, that CoPEP can be a reasonable process model for developing internet-based community platforms for cancer patients in the early stages. End user testing and continuous enhancement of community platforms are still not represented adequately in the process model. Therefore we want to extend the model and integrate automatically generated user information like click streams as well as user surveys. Another challenge refers to the application of the model for a mobile extension of the platform, like the development of interfaces for mobile devices (e.g. the development of a WAP-interface) and the development of mobile services for cancer patient communities (for more details see e.g. Leimeister 2003). Further problems are the little experiences with other user groups besides breast cancer patients. Potential user groups can be found throughout the whole healthcare area: other cancer patients (like lung cancer, etc.), patients suffering from other

chronic diseases like e.g. diabetes or even healthcare professionals. Figure 5 shows three major directions for the further development and application of CoPEP:

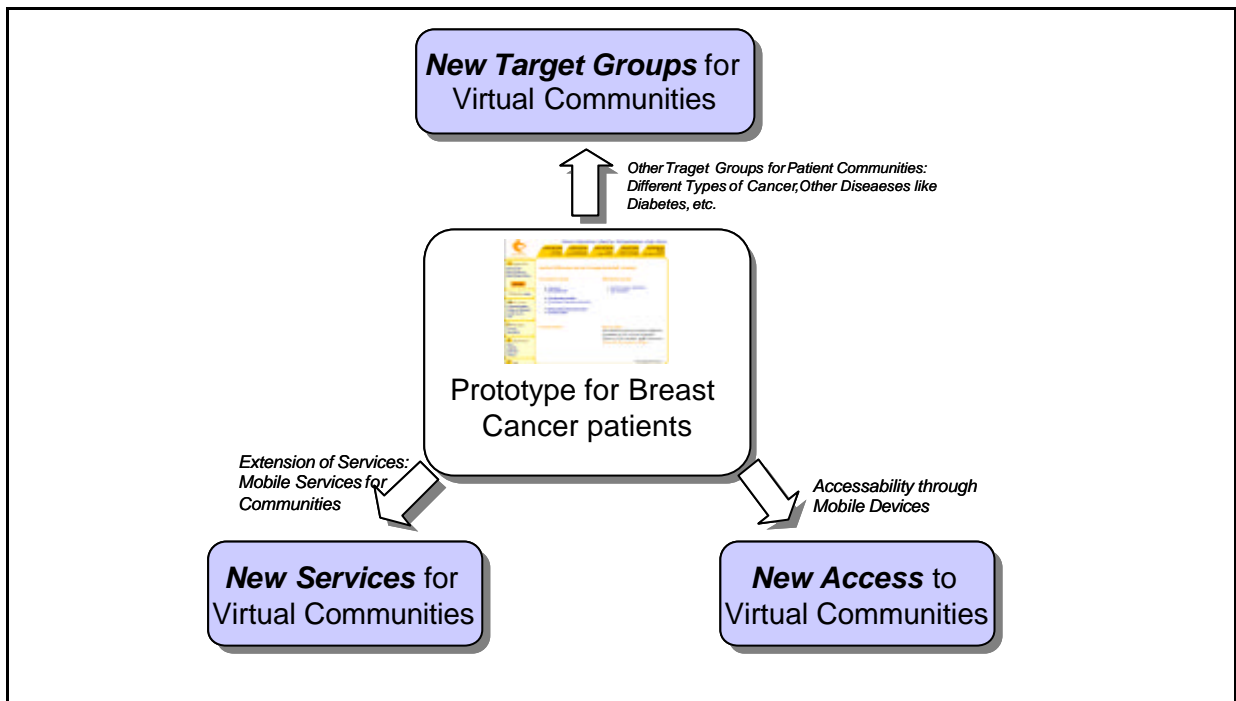


Figure 5: Further challenges for the development of virtual communities for patients

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