Mobile Virtual Healthcare Communities: An Approach to Community Engineering for Cancer Patients

Jan Marco Leimeister  
*Univ. Hohenheim, leimeister@acm.org*

Miriam Daum  
*Univ. Hohenheim, mdaum@uni-hohenheim.de*

Helmut Krcmar  
*Univ. Hohenheim, krcmar@uni-hohenheim.de*

Follow this and additional works at: [http://aisel.aisnet.org/ecis2002](http://aisel.aisnet.org/ecis2002)

Recommended Citation

[http://aisel.aisnet.org/ecis2002/70](http://aisel.aisnet.org/ecis2002/70)

This material is brought to you by the European Conference on Information Systems (ECIS) at AIS Electronic Library (AISeL). It has been accepted for inclusion in ECIS 2002 Proceedings by an authorized administrator of AIS Electronic Library (AISeL). For more information, please contact elibrary@aisnet.org.
MOBILE VIRTUAL HEALTHCARE COMMUNITIES: AN APPROACH TO COMMUNITY ENGINEERING FOR CANCER PATIENTS

Jan Marco Leimeister
Information Systems Department, Hohenheim University, 70593 Stuttgart, Germany
Tel.: + 49-7 11-4 59 37 06, Fax: + 49-7 11-4 59 31 45
leimeister@uni-hohenheim.de

Miriam Daum
Information Systems Department, Hohenheim University, 70593 Stuttgart, Germany
Tel.: + 49-7 11-4 59 37 06, Fax: + 49-7 11-4 59 31 45
mdaum@uni-hohenheim.de

Helmut Krcmar
Information Systems Department, Hohenheim University, 70593 Stuttgart, Germany
Tel.: + 49-7 11-4 59 33 45, Fax: + 49-7 11-4 59 31 45
krcmar@uni-hohenheim.de

ABSTRACT

In this paper we describe mobile virtual healthcare communities as a solution for meeting cancer patients information and interaction needs. After an introduction into the healthcare system and its potential starting points for virtual communities, we focus on cancer patients. We analyse their situation through field studies and identify information and interaction needs. On this basis we derive requirements for user centric socio technical system design for cancer patients. As at present no existing offers meet these prerequisite, we intend to develop and implement a mobile healthcare community for cancer patients. The objective is to introduce a socially accepted, technically stable and economically reasonable system. By the time of the conference we assume to have implemented this community platform.

1 INTRODUCTION AND BACKGROUND

1.1 Mobile Virtual Communities

Virtual Communities (VC) can be defined as a group of people who gather because of a common interest, problem or task and whose members interact independent of time and space ((Klein et al., 2001), similar definitions are also provided by Preece, (2000), and Armstrong and Hagel III (1996). 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. Combining traditional internet technologies with the new capabilities of mobile networks is an approach for coping with this “access at any time and from any place” challenge. The vision of mobile virtual communities implies a bridging between technology and user requirements and assumes that for example synchronisation between different devices permits a seamless interaction.
Mobile virtual communities have great potential to serve ubiquitous needs. Such an omnipresent problem situation exists in healthcare when patients develop a desire for information and communication (as a result of a recently diagnosed disease or implemented treatment, for example) which exceeds the offer of the treating physician. From the characterisation of mobile virtual healthcare communities as ubiquitous information and interaction spaces, we derive design requirements for VCs that are transferred into the healthcare domain and which are particularly relevant to the situation of cancer patients. Two topics are of special interest. Firstly, to what extent do mobile community services accomplish information supply and social integration? Secondly, how should specific service models for healthcare communities be constructed? Only socially accepted, technically stable and economically reasonable/manageable solutions can ensure sustainable success of mobile virtual healthcare communities.

1.2 The healthcare system in Germany

The clients of the healthcare system are patients. Further actors can be classified in institutions from an organisational standpoint and in involved persons from a social standpoint. Institutions can either be suppliers of goods or services (i.e., hospitals) or cost units (i.e., insurance companies). Persons involved can either be part of an institution or more generally part of the healthcare system or benefit recipient like patients. According to this structure there can be several starting points for virtual communities (see figure 1) corresponding to groups with similar interests, problems or common tasks. Examples are, groups of physicians wanting to share clinical experiences or research results with colleagues outside institutional boundaries or members/employees of health insurance companies desiring to seek or exchange knowledge.

![Potential starting points for virtual communities in the healthcare system.](image)

In the following text, we will concentrate on a community of cancer patients whose members have a shared interest in their disease. Due to the often severe, life-threatening situation of cancer patients, a highly time and space independent information and interaction demand can be stated (see also 4.2). Until now (status November 2001) a working virtual community for cancer patients could not be identified on a European level (German or English speaking). According to the authors’ own inquiries, first approaches toward virtual cancer patient communities can only be found to exist in the U.S. (Daum et al., 2001, see also 4.1).

---

1 This paper resulted from of 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 Viag Interkom GmbH & Co. The project is promoted by the German Ministry of Research and Education. For further information please visit the website: [http://www.cosmos-community.org](http://www.cosmos-community.org)
Cancer diseases rank second, behind heart and circulatory diseases, as a major cause of death in adults in Germany. The number of new incidents of cancer in Germany in men is approximately 164,900 and in women 173,400 new cases are diagnosed each year (Deutschland, 1999). With respect to chronic diseases, cancer lies after diabetes on rank two of the most frequent illnesses. Cancer patients are also the second largest group of recipients of rehabilitative services in Germany (Deutschland, 1999). Direct economical costs of cancer are hard to quantify, careful estimations for Germany begin at the level of two digit billion Euro amounts (see also (Leimeister et al., 2002)). Indirect costs, caused for example by the loss of life, and work time as well as invalidity are difficult to estimate; but advances in therapies and adjuvant treatments are helping to stem the growth of these costs. An improvement in the level of patient information and knowledge related to disease and treatment can be viewed as contributing to overall therapeutic advances (Shepherd et al., 1999, Eysenbach, 2000). The National Advisory Council to the German Government stated in its report 2001 that competence and participation of patients are crucial elements which influence positively the improvement of process and result quality of the whole healthcare system (Gesundheitswesen, 2001). Thus the situation of patients can be improved through an extension of their competences and through more participation. Prerequisites for participation and enhancement of patient competences are reception and forwarding of information at all levels of the healthcare system.

The healthcare system in Germany has to deal with great challenges in the years to come. European integration, deregulation and liberalisation are impacting all areas of the already strained health care system. Hospitals, health insurance agencies, physicians and other medical professions as well as pharmaceutical industries have to prepare for competition. This leads to a stronger position of the healthcare system’s clients, the patients. Since information and interaction demands of patients have risen steadily over the past years (Gesundheitswesen, 2001), we see a growing potential for services such as patient information systems. Additionally, as competition for clients becomes stronger, customer service issues such as patient relationship management and patient retention will also become more important to institutions of the healthcare system.

1.3 Oncology patients’ information and interaction demands

Patients’ needs and demands for information often increase after a diagnosis of a disease or during medical treatment (Shepherd et al., 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.

\(^2\) We would like to thank Mrs. Carol Krcmar for her valuable contributions to an earlier version of this paper.
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 mobile virtual healthcare communities as ubiquitous information and interaction spaces for solving these problems. The important role of access to relevant and actual information and interaction with peers is supported by results of the National Advisory Council to the German Government which declares in its 2001 report information supply for patients as inappropriate on a general level as well as on the level of supplier and recipient of services (especially on the level of physician and patient). 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. Therefore, improvements in the German healthcare system specifically related to improving the quantity and quality of patient-centred information is recommended (Gesundheitswesen, 2001). What role information systems in general and mobile 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.

2 CHALLENGES FOR VIRTUAL HEALTHCARE COMMUNITIES

2.1 Scenario: A day in Christina M.’s life in a virtual healthcare community

One year ago, Christina, 34 years old, was feeling tired. She went to her physician and two days later, on a Friday afternoon, her physician told her: I regret to inform you that you have been diagnosed with leukaemia. Christina went home, shocked and afraid of things to come. A good friend told her about a virtual community for leukaemia patients. There she found information about the diagnosis, treatment and answers to other questions. But the most important thing was she could share her fear with other patients in the same or similar situation, who were the same age and had the same type of cancer. Beyond this she could contact survivors of leukaemia. Christina realised her life wasn’t over. The stories of other patients encouraged her and gave her hope and strength. In this cancer community people could understand her and her problems, by far better than her family and friends.

Today Christina is one of the most active community members. Her personal assistant/mobile phone enables her to have access to her own data/history of illness, to medical data bases, to a personal calendar with an e-mail reminder service for the next appointment, the internet and her cancer
community. Christina can access her community from any place at any time. Christina likes to write e-mails whenever and wherever she wants to, especially when she has to go to the hospital for a longer stay. In her personal diary on the community platform she writes down how she is feeling. Her physician can access this data and interfere if something important occurs and can give her advice. In addition, the community offers her location based services, enabling her to look for friends nearby or search for the next physician or pharmacy. And if she is in a life-threatening situation, the mobile device enables her to send an emergency call. Via the mobile device her physician or the ambulance can precisely locate her.

2.2 Service Models for virtual Healthcare Communities

The visionary example of Christina’s life in a virtual healthcare community shows some of the possible benefits of applied information systems. In our research we address the following issues:

1. What are the needs for information and interaction of cancer patients?
2. What web-based and mobile services are particularly effective to improve the situation of these patients?
3. What are effective designs for mobile information systems in the healthcare sector, particularly for patients?

Community platforms offer various services. A service can be defined as an exchange of information over a network for certain devices on the basis of standards. It assures that information is distributed and that interaction can take place. In the context of community platforms we consider a service to be those features that enable information and interaction. The service “chat”, for example, enables synchronous, written communication between people who are not at the same place.

Services for mobile virtual healthcare communities can be put into three categories: Generic (not personalised or context sensitive), personalised information, and interaction services. If they are accessible through conventional internet access devices such as PCs, these services are labelled as web-based services. If they are accessible through mobile devices, they are considered as mobile services. Figure 2 visualises this categorisation of community services with some examples.

Figure 2: Service categories for mobile virtual communities
The most challenging questions for research lies in the user-centric development of services. The methodological way towards analysing user needs and the translation of user demands into a design of information systems is described in chapter 3.

3 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 will be implemented. The objective of this venture is to plan, build, introduce and evaluate IS-platforms for cancer patient communities. Pilot projects are a special version of interventionistic science: They develop and implement technological innovations in their natural organisational and social environment (Schwabe and Krcmar, 2000b).

Starting point is a socio-organisational problem (in this case the situation of cancer patients following hospital discharge). At the beginning stands the in-depth analysis of the situation of cancer patients through literature review and case studies, using interviews, questionnaires, observations and document analyses (Yin, 1989). The perspectives on the research objects for analysis are deduced from the Needs-Driven-Approach (NDA) by Schwabe and Krcmar (1996). The NDA was originally developed to design tele-cooperation (Schwabe and Krcmar, 2000a). It analyses tasks, work processes, interactions of actors, social structures, tools and shared material, adoption and diffusion of technology, and information storage (Schwabe and Krcmar, 1996). These perspectives are the basis for designing interview guidelines, analysing documents in self help groups, constructing questionnaires and all other methods used in the phase of field studies (see also chapter 5). 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 takes place and thus iterative learning steps of the system developer can be augmented at all stages. Thus this pilot project can be considered a level-three pilot project, since it consists of analysis, design and implementation of an information system (Schwabe and Krcmar, 2000b).

4 PRELIMINARY RESULTS

4.1 Field Studies

The objective of the field studies was to evaluate 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 at 5 different cancer self help groups with approximately 100 active members. Semi-structured interviews, observations and document analysis were utilised for this ethnographic analysis. Following this step, web-based information and interaction offers were investigated. Finally, identified cancer patients’ needs and already available offers were compared.

Figure 3: Elements of conducted field studies
Cancer patients’ situation: From October 8th-12th 2001 the European week against cancer took place. 800 persons attended the event in Stuttgart. Lectures were presented on intestinal, breast and lung cancers. During this event, a standardised questionnaire was distributed to approximately 500 persons. The rate of return was 116 questionnaires (23%). 85 of the completed questionnaires were from females, 30 from males and one n. a. The average person was 58 years old. Among the 116 persons were 69 cancer patients (59.5%), 33 relatives of cancer patients, 15 “others” and 3 n.a. 52 of the females and 16 of the males were cancer patients. Of the 69 cancer patients, 28 (40.6%) were members of self help groups; 23 females (44.2% of the female cancer patients) and 5 males (31.3% of which 1 man was not a cancer patient). The fact that 40.6% of the cancer patients were members of self-help groups isn’t surprising as patients attending such events tend to be active, open-minded persons and therefore very often members of self help groups. The following numbers refer to male and female cancer patients, including cancer patients who didn’t answer all questions completely. 13.5% of female and 50% of male cancer patients agreed fully and 44.2% of female and 25% of male respondents agreed partially that their physician has a substantial information advantage. 11.5% of female cancer patients, 25% of female respondents and 31.3% of males agreed partially to the statement that they want to look for information on the internet. 28.8% of female cancer patients reported using mobile phone as well as the internet. Only 56.3% of males reported using mobile phones and 43.8% surf the internet. 25% of the females, 43.8% of the males agreed fully and 34.6% of the female and 31.3% of the male cancer patients agreed partially that they want to communicate more with other patients. These statements emphasize the need for web-based or mobile information and interaction, e. g. partner matching services.

Ethnographic analysis of self help groups: Five narrative interviews with self help group leaders and several semi-structured interviews with members showed that there is a lack of information and interaction possibilities in general. The patients want and need information about their specific type of cancer. The local self help groups in this study included two breast cancer groups, two groups with intestinal cancer and a group for leukaemia and lymphoma. Additionally, four semi-standardised expert interviews were conducted with members of health insurance companies, cancer information centres, an oncological medical centre in Stuttgart and the Interdisciplinary Cancer Centre of the University of Tuebingen. The following analysis is made on the basis of the Needs Driven Approach (Schwabe and Krcmar, 1996) perspectives, since these perspectives facilitate the “translation” of analysis results into systems development (Schwabe and Krcmar, 2000a).

Information storage: In the self help group the group leader and other members collect information such as brochures from the umbrella organisation, updates on therapeutic advances and/or news about cancer from the local newspapers. This information is exchanged during the meetings and distributed to members who are most interested in. Information about the “best” physicians and hospitals and tips on what to do if treatment is unsatisfactory is exchanged as well. The information handed out is copied and given back to the leader. Personal data and the copied informational materials are collected in a private folder, in drawers or not at all.

Processes and Interactions: Processes of self help group meetings varied between the different groups. The meetings take place between twice a month or once in three months, either in a public room or in a members’ house. Even if the meetings only took place quarterly, members called each other by telephone very often to seek and receive advice. Some members had to travel long distances to self help group meetings, sometimes more than 100 km (about 62 miles). This fact shows the importance of the self help group for its members.

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 experienced feelings of hope and encouragement when they saw one of the members doing well. Information on alternative therapies was often exchanged; for example, that mistletoe, alga or various vitamin preparations had helped one of the group members, even though the effect was from a medical point of view not proven. Personal problems, loss of hair, sexual problems or difficulties with employers and/or pensions were also discussed.
Social structure of self help groups: The social structure describes who is interacting with whom and in which way. Among the analysed groups this was different and depended on the size of the group. The larger the group and the more members it had the more likely that smaller subgroups seemed to emerge. The central person in all groups was the leader. Sometimes there were outsiders or new members in the groups who were usually “mentored” very quickly by older group members. Role pattern could be identified.

Analysis of materials and tools: The use of materials and tools such as mobile phones, personal digital assistants or the internet seemed to be dependent on the average age of the group. In some groups, such as the one for women with breast cancer and the one for leukaemia and lymphoma, almost all of the members had mobile phones and used the internet. In other groups the majority of the used material was paper-based like brochures.

Remarkable is that most members of self help groups emphasised the important role of access to other patients in similar situations and to relevant information. Unrestricted access to valid, understandable and relevant information as well as the possibility to contact other patients/members of the self help group at any time was considered to be very important. Each of the groups analysed used telephone lists to foster communication between members. Each group member was encouraged to call other members whenever necessary. While this approach serves members of self help groups, it is, unfortunately, not available for the majority of cancer patients.

Our results confirm that cancer patients demand and need information and interaction services. In the following we will analyse available offers for cancer patients on the web.

Web based patient information and interaction offers: A study of one hundred websites in German and English attempted to analyse the state of the art of this type of information provision for cancer patients (Daum et al., 2001). The analysed sites were categorised as introduced in chapter 2.2 figure 2. Information services can be differentiated into generic and personalized information. Generic information services offer information not referred to the individual situation whereas personalised information services deal with information especially processed for the individual. The second category are interaction services. These allow users to interact with others and thus to exchange their stories and experiences.

The study tried to simulate the way cancer patients seek information on the internet. Therefore the three most frequently used search engines in Germany were selected: http://www.google.de, http://www.altavista.de and http://www.yahoo.de. If a patient was searching for ‘krebs + information’ (‘cancer + information’) he could receive between 40 and 23500 matches. Patients most likely use a combination of methods to search on the web including searching for specific information about a specific type of cancer. This study, however, tried to give an overview of the information and interaction services for cancer patients in general. The hits related to cancer specific information were chosen and other sites were excluded. At most, the first 50 hits were scanned. After that the results were accumulated and redundant hits were deleted. At the end, 24 websites remained. Those websites were analysed and from these websites the researchers clicked through the recommended links. By this „snowball technique“ 76 other websites could be selected. This is a conscious sample technique to analyse social networks where no complete survey is possible (Schnell et al., 1999). The 100 analysed websites consisted of 51 from Germany, 6 from Austria, 3 from Switzerland, 38 from the USA and 2 from Great Britain. The country of origin was deduced from the registered office/address of the operators of the website or from the top-level domains of the URLs.

Important results of this study are that most of the websites have generic information such as news on cancer research and therapy and links to other websites. Remarkable is that there are many similarities between German and English websites relating to the generic information services. One difference is that suggested books/literature are offered by 15% of the English and 40% of the German web pages, whereas personalized information services could be found only on English-language websites. Only a few (nine American) websites offered personalized information, e.g. a personalized starting page or a personal web page, according to personal profiles filtered information, a personalized calendar or e-
mail reminder services related to, for example, the next physician’s appointment. None of the analysed
topics were offered mobile services. Most websites had interaction services such as e-mail (ca. 90%),
discussion lists/bulletin boards (ca. 30%) or chats (20%). There was, however, in only a few cases a
remarkable quantity of traffic. According to our definition of virtual communities, we considered
websites with interaction services and a discussion board with more than five postings
per day as a community. According to this definition, only nine websites can be called a community.
This appropriation was chosen because of the lack of possibilities to measure other indicators for ‘a
sense of membership or ongoing rhythm of social interaction’ among the users (Mynatt et al., 1997).

In the majority of cases, hosts of the websites are associations and institutions, companies (especially
pharmaceutical companies) or private persons like cancer survivors, physicians, care-givers or family
members. In detail 64% of hosts are associations and institutions, 18% private persons and 14%
companies. Hosts for 4% of the sites could not be identified. We found that 71% of the websites got
their funds from sponsoring, donations, government support or membership fees. 14% had banners,
4% generated income through provisions and 3% had a shop where they sell their products on-line.
In Germany the websites offered mainly generic information, none offered personalised information
services. Interaction services were offered at German and English websites by less than one third if the
possibility to write e-mails is not counted. These results demonstrate the potential for virtual
healthcare communities and thus for the COSMOS project to meet cancer patients’ information and
interaction needs.

4.2 First steps of system design

Our research has shown thus far that a socio-technical design for virtual healthcare communities has to
consider the following issues (among others) to be successful:

1. Creation of a virtual information and interaction space with appropriate communication
   channels according to cancer patients’ needs.
2. Access-right structures that support the development of trust and that support real-life
   situations and interactions.
3. 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 period of time
   (Nunamaker et al., 1997).
4. The facility for an active community-management to remotely 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 such as
   charlatanism, etc.).

Cancer patients migrate between different contexts; various hospitals and medical centres, work and
home. Hospitals or medical professionals still remain the most important source of information, but
information and interaction desires are ubiquitous and are not confined to office hours of physicians.
In addition, there are other needs more than just medical knowledge retrieval. The desire for social
peer-to-peer interaction and emotional support are independent of time, costs, stage of disease,
 mobility and/or of structures inherent in self help groups. Opening oneself to others and dealing with
very intimate and private issues requires an intimate environment. Trust could be, 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 using 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, 2000a)). Its advantages, from the standpoint of software engineering, can be attributed to several aspects. First, 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, 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 and documents and have direct communication with others only after having them invited to join. A “public room”, where both 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 usual social group structures combined with the wish for unrestricted access to information and spontaneous interaction with others.

Further specifications for software-design can be made for the service-model and classified into four areas: Adaptability, awareness, collaborative filtering and interaction.

Adaptability means that the platform has to be adapted to the individual needs of the single cancer patient, to group-needs such as those of self help groups, and to the general situation or to the organisational context like the legal circumstances (Prinz, 2001). Awareness refers to the understanding of actions of others which provide a context for own user actions (for further details see also Teege et al., 2001). Examples for this are notifications of presence of other group-members or special friends or alerts on specific events. Filtering relates to the process of selecting a subset of information objects out of a larger set. Collaborative filtering adds directly or indirectly other users’ experiences to the filtering process by considering their prior actions in similar situations (Koch, 2001). If a user searches for information on subject X the platform might indicate that other users who have been looking for similar information also checked information on subject Z. Interaction refers to all services which enable users to communicate with one another.

These four mechanisms can be combined to several services designed to user needs. Here are some examples: Searching for other persons with similar problems can be supported by partner-matching functionalities based on user profiles either user-generated or automatically generated or combined profiles. A personalised entrance to the public room can be used to enable users to personalise “their own” information-updates from the community and to check on other users’ presence in the community.

Once the socio-technical design is completed the next challenge will be the implementation of the prototype in its natural setting. In order to achieve a high level of user acceptance, we will develop an implementation design embedded in the organisational context of our COSMOS-Healthcare project partners. Starting with the migration of existing self help groups onto the platform and with marketing activities in major hospitals through medical staff we plan to launch the first web-based community platform for cancer patients in the greater Stuttgart area by April 2002. Successively an extension of services for mobile devices is planned in the months to follow.

5 SUMMARY AND OUTLOOK

Mobile virtual communities are a very promising approach for overcoming information asymmetries and for supporting interaction in the healthcare sector in general. This seems to be an especially promising model for cancer patients and this group demonstrates strong and ubiquitous demands for valid and trustworthy information. Further, as the results of this as well as other studies indicate, cancer patients are likely to seek 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 should look like. By the time of the conference we expect to have designed and implemented the first mobile virtual community for cancer patients and will be able at that time to present further results.

6 REFERENCES


