Towards M-Communities:
– The Case of COSMOS[1] Healthcare[2] –

Jan Marco Leimeister
Information Systems Depart-ment
Institute for Business Admini-stration.
Hohenheim University, Germany
leimeister@uni-hohenheim.de

Miriam Daum
Information Systems Depart-ment,
Institute for Business Admini-stration.
Hohenheim University, Germany
mdaum@uni-hohenheim.de

Helmut Krcmar
Information Systems Depart-ment
Institute for Business Admini-stration.
Hohenheim University, Germany
krcmar@uni-hohenheim.de

Abstract

In this paper we describe mobile virtual healthcare communities as a solution for meeting cancer patients needs for information and interaction. After a short intro-duction into the German healthcare system and its poten-tial 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. Since no existing offers meet these prerequisites and some of the user needs identified hint at an extension of web-based services towards mobile services, we intend to develop and implement a mobile healthcare community for cancer patients.

Only socially accepted, technically stable and eco-nomically feasible solutions can ensure sustainable suc-cess of mobile virtual healthcare communities.

1. Introduction

1.1. Structure of the paper

After the abstract, chapter 2 starts with an introduction into virtual communities. Consequently the German healthcare system is described in brief, followed by a scenario for a virtual healthcare community. Chapter 3 outlines purpose and methodology of the project. The following chapter 4 describes preliminary empirical find-ings, beginning with the needs analysis of cancer patients. After that results of analyses on web-based information and interaction offers for cancer patients are summarised briefly. Implications of our empirical findings for the community engineering are described in chapter 5 and first steps of system design are mentioned. The next sec-tion describes the implementation of our community plat-form for cancer patients. Chapter 6 emphasises possibilities of adding value to virtual communities for cancer patients through mobile services. It pre-sents/introduces some mobile services, in particular for the healthcare sector. The papers ends with a summary and outlook for further research.

1.2. Mobile virtual communities

A Virtual Community (VC) can be defined as a group of people who gather because of a common interest, prob-lem or task and whose members are independent of time and space for interacting [1]; [2], for similar definitions see also [3-5] [6]. Virtual Communities provide ubiqui-tous information and interaction spaces. For being acces-sible and usable at any time and from any place, information and communication technology (ICT) is a crucial element. Combining traditional internet technolo-gies with the new capabilities of mobile networks is an approach for coping with this challenge. The vision of mobile virtual communities implies a bridging between

---

technology and user requirements and assumes that e. g. synchronisation between different devices permits a seamless interaction. Mobile virtual communities have great potentials to serve ubiquitous needs. Such an omni-present problem situation exists for instance in healthcare, when patients develop a desire for information and communication exceeding the offers of the treating physician. These information demands vary over time and during certain status of treatment and illness [7].

In order to achieve ubiquitous information and interaction spaces, we derive in the following design requirements for VCs that are transferred into the healthcare domain, particularly into the situation of cancer patients. Special emphasis is put on the possibilities and challenges of mobile technology.

1.3. The German healthcare system

The clients of the healthcare system are the patients. Further actors can be classified in institutions from an organisational standpoint and in involved persons from a social standpoint. Institutions can either be supplier of goods and/or services like hospitals or cost units like insurances. 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 a similar interest, problem or a common task. Examples are groups of physicians which want to share experiences beyond institutional boundaries or groups of members/employees of an insurance which have the common interest of exchanging knowledge. And of course patients with the same disease (like cancer), which will be the target group o this work.
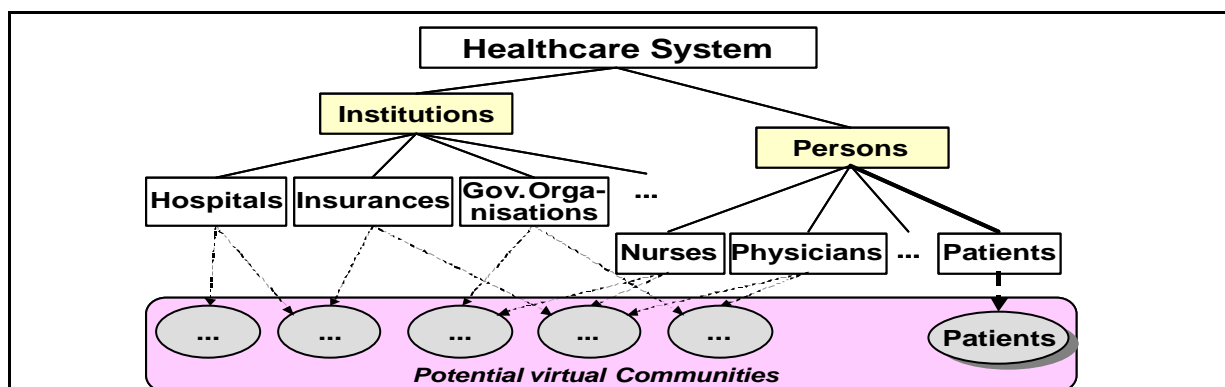

Figure 1. Potential starting points for virtual communities in the healthcare system

1.4. 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 for leukaemia. Christina went home, was shocked and afraid of the things coming. A good friend told her about a virtual community for leukaemia patients. There she found a lot of information about the diagnosis, treatment and other questions. But the most important thing was she could share her fear with other patients in the same or similar situations, the same age and 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/story 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 these data and interfere if something important occurs or can give her advices. In addition to that 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 sends an emergency call. Via the mobile device her physician or the ambulance can localise her precisely.

2. Purpose and methodology

2.1. Purpose

The objective of the research project is to offer cancer patients a community platform that meets their needs. These specific needs are identified through ethnographic field studies, document analysis and interviews. The preliminary results are that a platform where patients can exchange their opinions towards a certain drug, physician, therapy or their personal experiences might satisfy their needs. Because lots of patients do not have the time or the possibility or they do not want to go to real self help group meetings, the virtual and mobile community is a possible way out of this problem. They can access their community providing information and contact to other patients at any time and at any place. Furthermore mobile devices offer new and interesting services in the healthcare sector.

2.2. 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 an IS-platform 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 [8].

Starting-point is a socio-organisational problem (in this case the situation of cancer patients after returning from hospital). At the beginning, an analysis of cancer patients` situations will be performed in depth through literature review and above all case studies, using interviews, questionnaires, observations and document analyses [9]. 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 analyses, following the tradition of using ethnographic analyses for system design in medical informatics [10-12]. The field studies and the constantly made experiences influenced the system design and requirements. As we know our particular population of users (these are cancer patients, relatives and friends) we were able to find out their specific information and interaction needs.

After that, web-based information and interaction offers were investigated. Finally, identified cancer patients' needs and already available offers were compared.
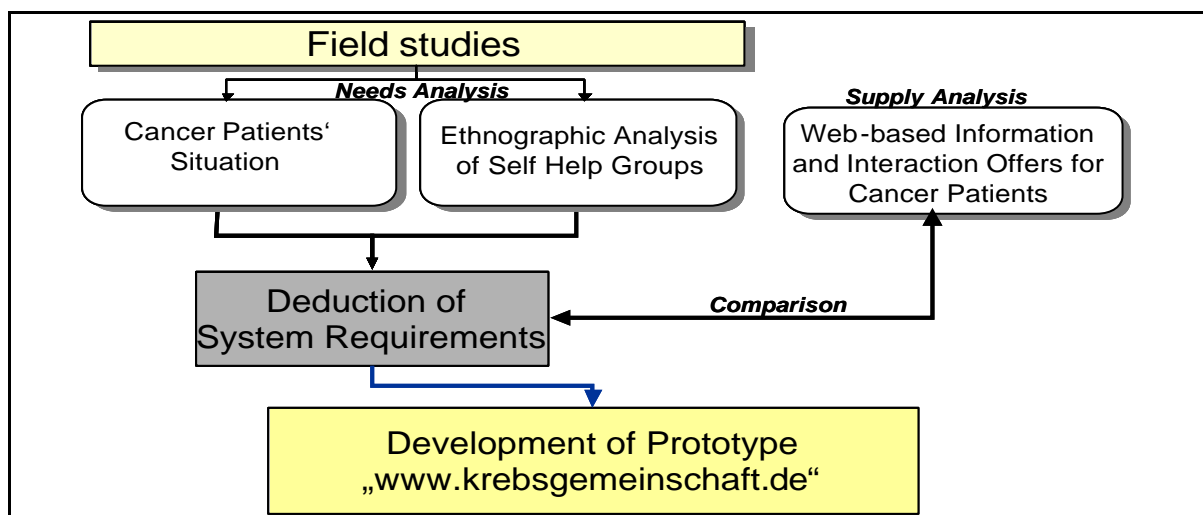

Figure 2. Research plan

3. Empirical findings

3.1. Needs analysis of cancer patients

Patients develop very often high information demands, e. g. after a diagnosis of a disease or during medical treatment. Jones et al [13] stated that 80% of the patients want as much information as possible. They might want to control diagnosis or take part in the decision process on further treatment based on made diagnosis.

During the European Week against Cancer (October 2002), a standardised questionnaire was distributed in Stuttgart, Germany to approximately 500 visitors. The rate of return was 23,2 % (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. 29% of the female cancer patients use mobile phone as well as the internet, by men mobile phones are used by 56% and the internet by 44%. More than two thirds agreed in parts that they want to communicate more with other patients. These statements emphasize the need for web-based and/or mobile information and interaction services and show a chance to be successful with such a platform.

Additionally, we conducted ethnographic analyses of self help groups. Therefore we lead narrative interviews with self help group leaders and several semi-structured interviews with group members. The results showed that lack of information and interaction possibilities for cancer patients and their relatives could be stated. 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 gained new hope and got 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 very long distance to cover (sometimes up to several hours drive) in order to get to their self help group meetings. This fact underlines the importance of 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 three of five groups the majority of members had mobile phones and up to a third already 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 seems to be only possible for members of self help groups and therefore not for the majority of cancer patients. Only 3% of the cancer patients attend self help group meetings [14]. Hence our results confirm the demands of cancer patients, their relatives and friends for information and interaction services and the need for an offer also addressing patients not already associated with self-help-groups.

3.2. Analysis of web-based information and interaction offers for cancer patients

In order to analyse offers for cancer patients two internet surveys have been conducted [15, 16]. Until now (status May 2002) there are only a few websites with significant levels of interaction which could be called a community on a European level (German or English speaking). These are less than 6% of cancer related websites. Most of the studied websites (n=276) offered information, either medical or personal like those based on personal experiences. In the German and English speaking internet, we could not identify any offer concerning mobile services support for access through mobile devices.

For further information and the results of the years 2001 and 2002 see [15, 16].

4. Implications for community engineering

4.1. First steps of system design

Our research and preliminary results have 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 [2]):

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 also support real-life situations and interactions. Similar results can be found at [6].
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 [17].
4. 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 [18], 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 re-

trieval. The desire for social peer-to-peer interaction and emotional support is independent of time, cost or stage of disease and mobility and also of structures required by self help groups [14]. 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 [19]) 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 [20]. 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 [21]). 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 it supports existing ways of cooperation and coordination in social structures [21]. 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 and links, and have direct communication with others only after having invited them to join, called "my site". In a "public room", all members and visitors of the virtual community can see all information and documents and search for information. This is represented through those parts of the website where no log-in or registration is required. A "group room", which is restricted to members of a group (e. g.

is restricted to members of a group (e. g. like the self help groups) and provides access to all documents in this group room and all group related issues to all group members. 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. That means that the user can choose if he wants to be anonymous, a lurker, a registered member, active or passive. He can decide how much other users get to know about him. It is possible to change the personal profile whenever needed.

4.2. Implementation of a community-platform for cancer patients

In order to fulfill diverse requirements on a community-platform, a client-server-solution is utilized whose architecture consists mostly of three layers (data, application and presentation layer). This architecture allows a high scaling and flexibility of the system as well as extensions by contextsensitive elements. It also offers the advantage of making a modular structure of the platform possible. Furthermore, different standards as for example XML/XSL, HTML, WML, JDBC and HTTP(S) are supported by this system, thus permitting a support of any access device using a browser (web-browser, WAP-mobile-browser, etc.).
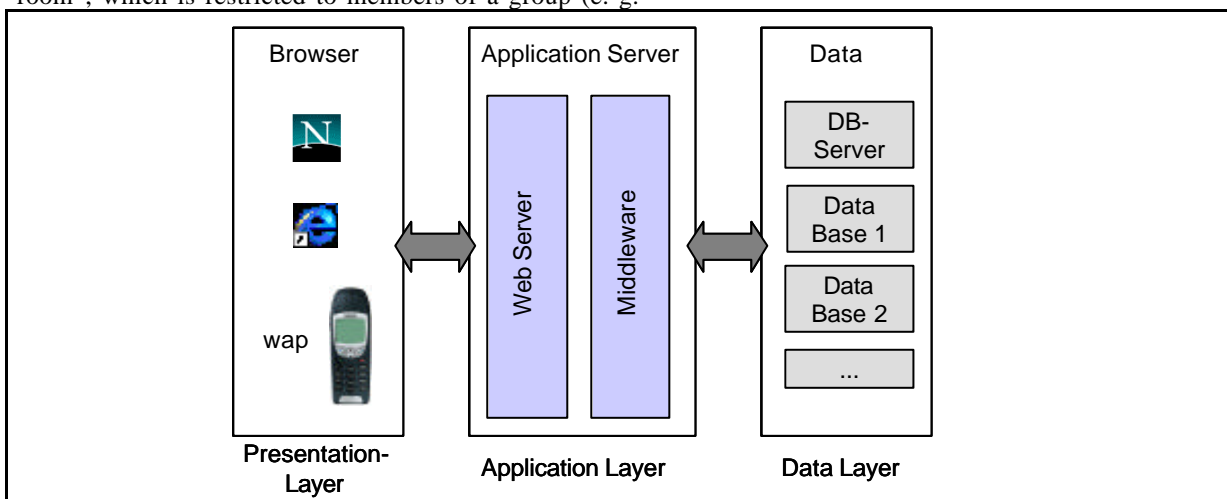

Figure 3. 3-layer-architecture of community-support-systems

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-compatble 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 devel-

oped independently of the system on which they are based in each case. Thus, for example the integration of existing data sources can be managed.

5. Adding value to virtual communities through mobile services

The architecture of the community platform and the application of XML as a data retention format enables the general extension of the community-platform through mobile services. Mobile services can add value to traditional web-based communities for several reasons. They extend and/or improve already existing services or they allow new services that have not been possible before. Figure 3 visualises some possibly value-adding services.
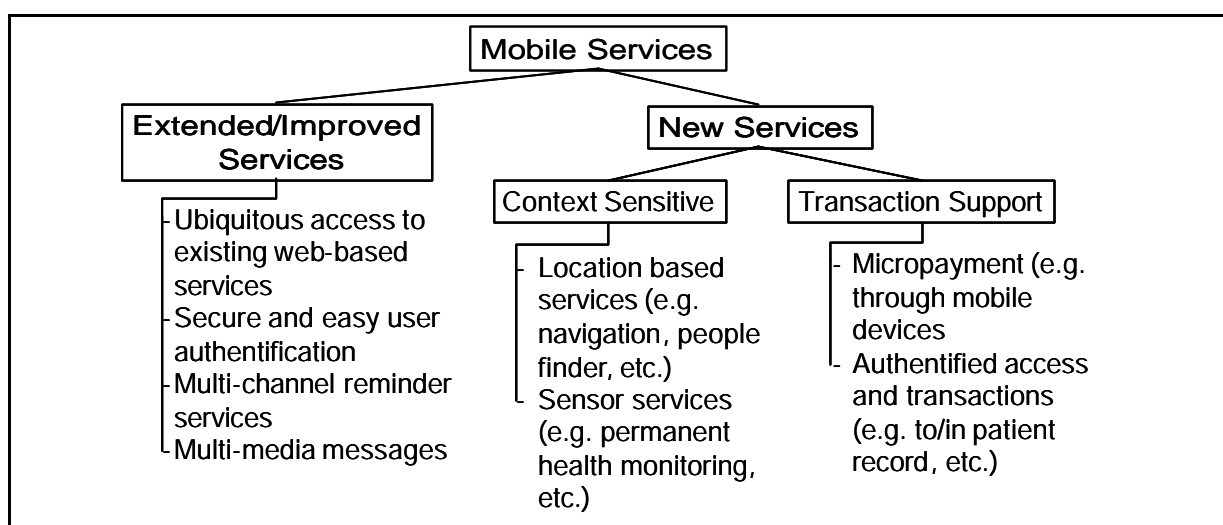

Figure 4. Mobile services for adding value to virtual communities

Through ubiquitous access to already existing web-based offers, community members have for example access to information and the possibility for interaction with others at any time and at any place. That means that 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 easy and feasible possibilities for user identification (e.g. automated log-in procedures, etc.).

Another improvement concerns already existing reminder services on the internet[3]. SMS-based reminder

services supplement these services, for instance reminder for the next medical examination or especially for drugs/pills, are by far more efficient[4]. 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 last service in this category is multi-media messaging. It describes the integration of voice mail, e-mail and fax applications into one messaging display.

The other class of mobile services are the "new services" that are only made possible through the new possibilities of mobile devices. These devices are capable to support context sensitive and location based services. That means for instance that awareness services of who (buddy) or what (location) is around can be perceived and

---

[3] An example for an e-mail reminder service for the next physical examination for breast cancer patients can be found on http://www.nabco.org/index.php/30.

[4] For examples see MPill (http://www.m-plify.com/m-pill/) a drug reminder per SMS as well as m-therapy (http://www.m-therapy.de/) or cura call, a vaccination or a preventive medical check-up reminder per SMS (http://www.dicomzip.de/).

processed by the mobile devices. These services can either be push or pull services. Push service means that information is offered by the mobile device without any previous request by the user, e.g. 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 demands. Furthermore, it is possible to choose context and location attributes for selecting contacts. One thing is that people can get awareness information about their buddies and the second thing is that they can get a message generated by the system that a certain person (so far unknown) is around and that this person is interested in the same location or for example music band. This kind of matchmaking is generated automatically by the system an enables spontaneous meetings. It discovers/identifies similarities and displays them [22]. Of course the users can specify rules and parameters like when, how and for whom they want to be reachable. One imaginable scenario is that all people who belong to a certain group (like breast cancer patients in general) and are near a self help group meeting current taking place get a welcome message and an invitation to join the group.

Another new kind of services in the medical field are emergency services[5]. 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[6]. Another project[7] deals with location based information systems. Via a mobile device it is getting possible to find the way to almost every location. The device shows the user a model of the surrounding as well as information about the location or the objects and buildings nearby. Any geographical position is connected with the information required there, made possible through Global Position System (GPS) and mobile internet access. Thus a digital model of the current surrounding occurs on the display of the device. Furthermore it is possible post virtual notes/messages bound to a location and to comment them.

Further categories of new mobile services deals e.g. with transaction support. For instance, Micro-payment refers to the possibility to pay via a mobile phone. The mobile device is connected with an bank account or the phone bill is charged. In order to pay in the internet or for example a taxi-driver you have to enter your personal PIN

and than the money is transferred[8]. But there are many more possible applications to come in the field of mobile services. The challenge for community engineering lies in identifying target group relevant services and integrating these services into a community platform. In order to be prepared for mobile services to come we have chosen an architecture for the community-platform for cancer patients that provides us with a maximum of flexibility referring to development and integration of new services towards the vision of mobile virtual communities for cancer patients.

6. Concluding remarks and outlook for further research

Mobile virtual communities are a very promising approach for overcoming information asymmetries and for supporting interaction in the healthcare sector in general. 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. Especially the aspects of ubiquitous access to a community and its members and services as well as new services enabled through new mobile technologies seem very promising. By the time of the conference we assume to be able to present first practical results from our research concerning designing, implementing and operating a virtual community for cancer patients and also the extension towards some mobile services.

7. References

[1]: Klein, A., J.M. Leimeister, and H. Krcmar, *Virtuelle Healthcare Communities*, in *Community Online Services and Mobile Solutions*, U. Baumgarten, et al., Editors. 2001, Technische Universität München: München. p. 17-30.

[2]: Leimeister, J.M., M. Daum, and H. Krcmar. *Mobile Virtual Healthcare Communities: An Approach To Community Engineering For Cancer Patients*. in *European Conference on Information Systems (ECIS)*. 2002. Gdansk.

[3]: Preece, J., *Online Communities - Designing Usability, Supporting Sociability*. 2000, Chichester, New York, Weinheim, Brisbane, Singapore, Tokio: John Wiley and Sons. 439.

[4]: Armstrong, A. and J. Hagel III, *The Real Value of Online Communities.* Harvard Business Review, 1996. **74**(3): p. 134-141.

[5]: Schubert, P., *Virtuelle Transaktionsgemeinschaften im Electronic Commerce: Management, Marketing und Soziale Umwelt*. Electronic Commerce, ed. N.S. Szypersky, B.;

---

[5] Helpino is a service for persons in emergency situations in general (http://www.helpino.com/), another example is the positioning through mobile phones for elderly or ill people and the possibility to contact them at the same time (http://www.rheingaucenter.de/html/news/1302rhsfl03.htm).

[6] For example see http://www.vitaphone.de for patients with heart diseases or for diabetic patients http://www.diabetiker-hannover.de/diab_hannover/news_frame.htm, http://www.mss-gmbh.de/diabhh.shtml.

[7] http://www.nexus.uni-stuttgart.de/

---

[8] For an example see (http://www.paybox.de).

Scheer, A.-W.; Pernul, G.; Klein, S. Vol. Band 1. 1999, Lohmar, Köln: Josef Eul Verlag.

[6]: Mynatt, E.D., et al. *Design for Network Communities*. in *Proceedings of the Computer Human Interaction Conference (CHI 97)*. 1997: ACM Press, Atlanta GA.

[7]: Leydon, G.M., et al., *Cancer patients' information needs and information seeking behaviour: in depth interview study.* British Medical Journal, 2000. **320**(7239): p. 909-913.

[8]: Schwabe, G. and H. Krcmar. *Piloting a Socio-technical Innovation*. in *Proceedings of the 8th European Conference on Information Systems ECIS 2000*. 2000. Vienna.

[9]: Yin, R.K., *Research Design Issues in Using the Case Study Method to Study Management Information Systems*, in *The Information Systems Research Challenge: Qualitative Research Methods*, J.I. Cash and P.R. Lawrence, Editors. 1989, Harvard Press: Boston, Mass. p. 1-6.

[10]: Forsythe, D.E. *Using Ethnography to Build a Working System: Rethinking Basic Design Assumptions*. in *16th Symposium on Computer Applications in Medical Care (SCAMC)*. 1992. New York: McGraw-Hill.

[11]: Forsythe, D.E. and B.G. Buchanan. *Broadening Our Approach to Evaluating Medical Information Systems*. in *15th Symposium on Computer Applications in Medical Care.* 1991. New York: McGraw-Hill.

[12]: Fafchamps, D., C. Young, and P. Tang. *Modelling Work Practices*. in *15th Symposium on Computer Applications in Medical Care (SCAMC)*. 1991. New York: McGraw-Hill.

[13]: Jones, R., et al., *Cross sectional survey of patients' satisfaction with information about cancer.* BMJ, 1999. **319**(7219): p. 1247-1248.

[14]: Hasebrook, J., *Krebs-Selbsthilfegruppen - Untersuchungen zu Bedarf, Funktionen und Wirksamkeit*, in *Onkologie im psychosozialen Kontext - Spektrum psychoonkologischer Forschung, zentrale Ergebnisse und klinische Bedeutung*, F.A.H. Muthny, Gunther, Editor. 1993, Roland Asanger Verlag: Heidelberg.

[15]: Daum, M., et al., *Webbasierte Informations- und Interaktionsangebote für Onkologiepatienten - Ein Überblick*. 2001, Lehrstuhl für Wirtschaftsinformatik: Hohenheim.

[16]: Daum, M., et al., *Webbasierte Informations- und Interaktionsangebote für Onkologiepatienten - Ein Überblick*. 2002, Lehrstuhl für Wirtschaftsinformatik: Hohenheim.

[17]: Nunamaker, J.F., et al., *Lessons from a Dozen Years of Group Support Systems Research: A Discussion of Lab and Field Findings.* Journal of Management Information Systems, 1997. **13**(3): p. 163-207.

[18]: Kaminski, E., et al., *Measuring patients response to received information.* European Journal of Cancer, 2001. **37**(Supplement 6): p. 387.

[19]: Gryczan, G. and H. Züllighoven, *Objektorientierte Systementwicklung: Leitbild und Entwicklungsdokumente.* Informatik Spektrum, 1992. **15**(5): p. 264-272.

[20]: Krcmar, H. and A. Klein, *Computer Supported Cooperative Work*, in *Lexikon der Wirtschaftsinformatik*, P.u.a. Mertens, Editor. 2001, Springer: Berlin. p. 113-114.

[21]: Schwabe, G. and H. Krcmar. *Digital material in a political work context - The case of Cuparla*. in *Proceedings of the 8th European Conference on Information Systems ECIS 2000*. 2000.

[22]: Koch, M., G. Groh, and C. Hillebrand. *Extending Online Communities into the Real World*. in *AMCIS 2002*. 2002. Dallas.