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# MOBILE COMMUNICATION AND COMPUTING IN HEALTHCARE: DESIGNING AND IMPLEMENTING MOBILE VIRTUAL COMMUNITIES FOR CANCER PATIENTS

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## ABSTRACT

*In this paper we describe mobile virtual healthcare communities as a solution for meeting cancer patients information and interaction needs<sup>1</sup>. 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. Since no existing offers meet these prerequisites we intend to develop and implement a mobile healthcare community for cancer patients. Three topics are of special interest. First, to what extent mobile community services accomplish information supply and social integration, second, how specific service models for healthcare communities have to be constructed and third what specifications a possible technical infrastructure has to meet. Subjects like ubiquitous community access, new possibilities of user identification and location related services are of special interest. Only socially accepted, technically stable and economically feasible solutions can ensure sustainable success of mobile virtual healthcare communities.*

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<sup>1</sup> 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 O<sub>2</sub> (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

## 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 are independent of time and space for interacting (Klein et al., 2001); (Leimeister et al., 2002), for similar definitions see also (Preece, 2000, Armstrong and Hagel III, 1996, 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. Combining traditional internet technologies 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 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 mobile virtual healthcare communities as ubiquitous information and interaction spaces we derive 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.

## 1.2 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 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 members/employees of an insurance which have the common interest of exchanging knowledge.

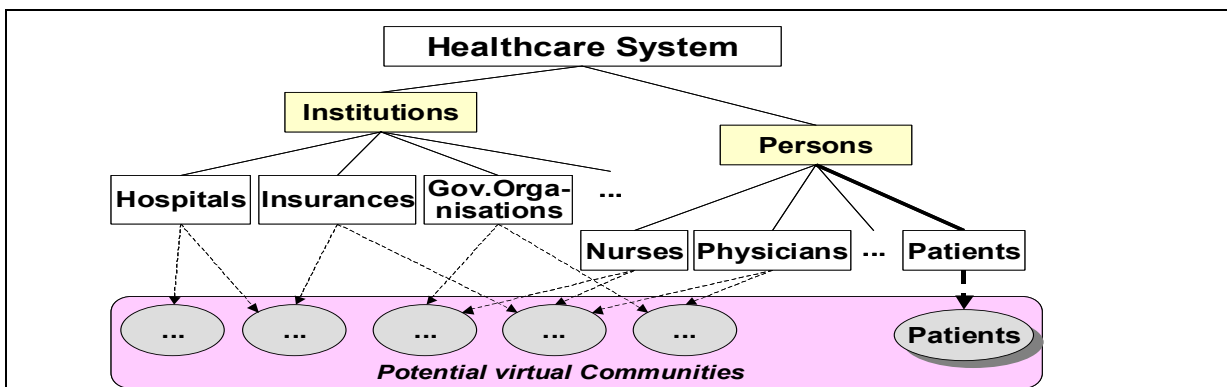


Figure 1: Potential Starting Points for Virtual Communities in the Healthcare System

# 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 and Krcmar, 2000b).

Starting-point is 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' will be 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.

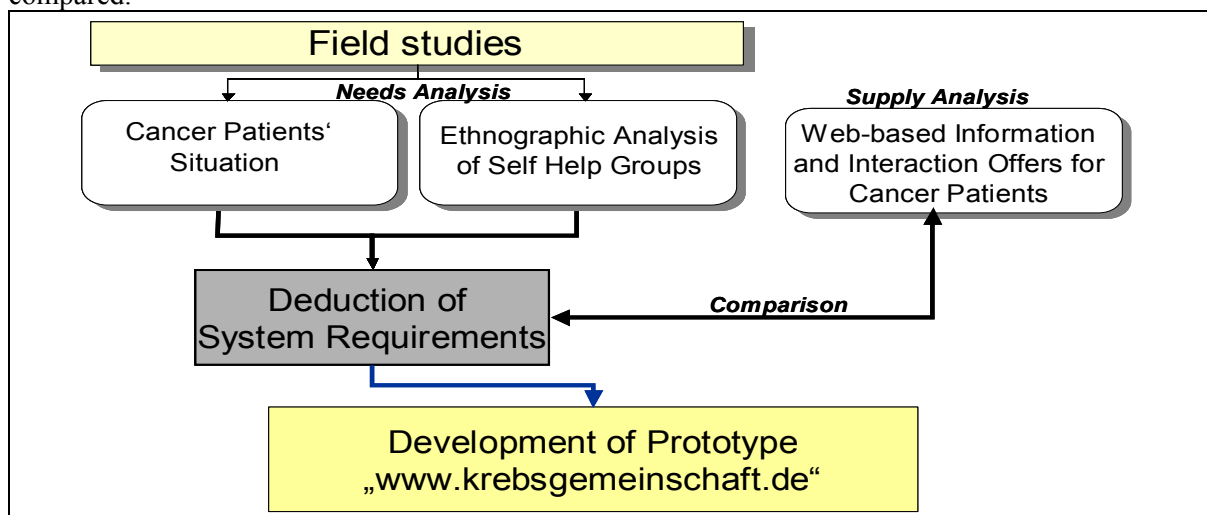


Figure 2: Research Plan

### 3 EMPIRIACAL 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. They might want to control diagnosis or take part in the decisions on further treatment based on made diagnosis.

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.

### **3.2 Analysis of web-based Information and Interaction Offers for Cancer Patients**

Until now (status November 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.

## **4 IMPLICATIONS**

### **4.1 First steps of 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 et al., 2002)):

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.
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 time (Nunamaker et al., 1997).
4. 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 and Züllighoven, 1992)) to provide useful digital tools and digital materials for cancer patients. Tools allow modification and processing of material. In tradition of Computer Supported Collaborative Work (CSCW), tools can enable users to communicate, to coordinate common tasks or to cooperate at shared material (Krcmar and Klein, 2001). Trust-related issues can be approached through a high priority of data-security and a highly specialised and scalable authorisation concept.

Therefore we propose an approach using the room-metaphor for software design (for details see also (Schwabe and Krcmar, 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 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, 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 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

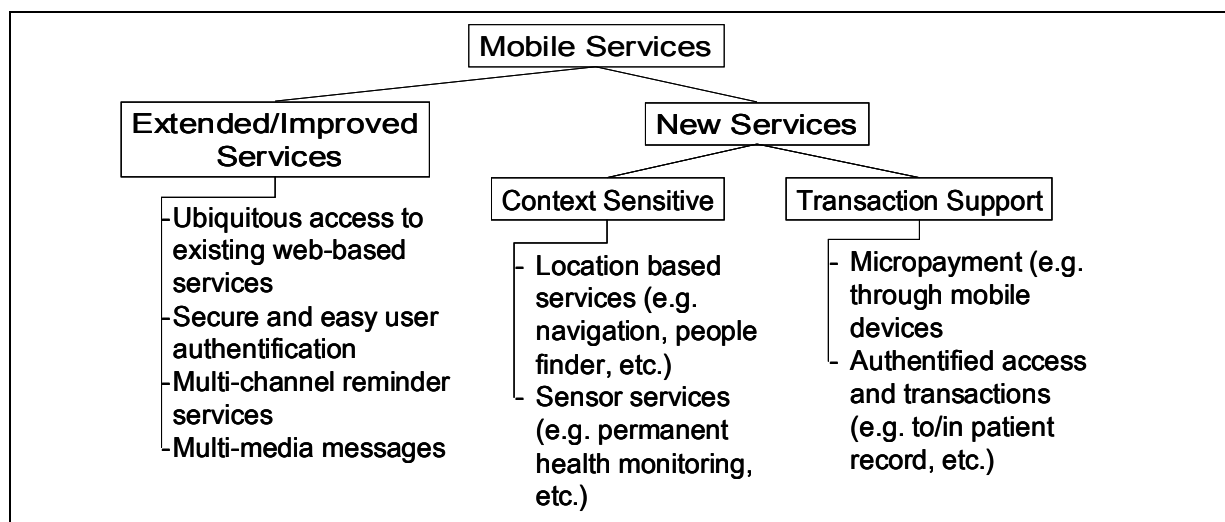


Figure 3: Mobile Services for Adding Value to Virtual Communities.

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.

## 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. 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 worth 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 valuable. By the time of the conference we assume to be able to present first practical results from our research.

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