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Designing and Implementing Virtual Patient Support Communities:

A German Case Study [1]

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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? What specifications must a possible technical infrastructure meet? The COSMOS project addresses these topics. Besides these aspects, new technological possibilities like mobile services and mobile devices are influencing virtual communities. Subjects like ubiquitous community access, new possibilities of user identification, and location-related services are of special interest since they might allow real anytime-anyplace access to the community platform. Thus new, value-adding services to community members could be added. But nevertheless: Only socially accepted, technically stable and economically feasible solutions can ensure sustainable success of (mobile) virtual healthcare communities.

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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 (for similar definitions see e.g. (Armstrong & Hagel, 1996; Mynatt, Adler, Ito, & O'Day, 1997; Preece, 2000; Schubert, 1999). Therefore virtual communities have great potential 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 resources of the treating physician. From the characterisation of virtual healthcare communities as ubiquitous information and interaction spaces, we have derived 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 cancer patients. In closing we put special emphasis on the possibilities and challenges of mobile technologies for virtual healthcare communities.

Research Design and Research Plan

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 (see Figure 1).

--- Figure 1 Goes About Here ---

As usual in pilot projects, the starting-point of this research is a socio-organisational problem (in this case the situation of cancer patients after they leave hospital). At the beginning, an analysis of cancer patient's situations was 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 were used for designing an IS-platform. This platform was implemented in the field, and 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 by 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

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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. Methods applied here were ethnographic analysis, semi-structured interviews, observations and document analysis. After that, web-based information and interaction opportunities were investigated. Finally, identified cancer patients' needs and already available interaction opportunities were compared.

On this basis the development of the prototype began, using an iterative process model 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.

Field Studies

Needs Analysis of Cancer Patients

Patients' needs and demands for information often increase after a diagnosis of a disease or during medical treatment (Sheppherd, 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, such as participating in self-help groups, can play an important role in dealing emotionally with a disease (for an overview see 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 (e.g., Eysenbach, 2000), the potential benefit of cancer-related communities becomes evident. However, the diversity of 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, all combine to make coping with cancer, even through participation in virtual communities, extremely difficult.

Recent research on cancer patients' informational demands (e.g., Kaminski, Thomas, Charnley, & Mackay, 2001) demonstrates a strong information interest in the following areas: Side effects/how I will feel; Explanation of disease and prognosis; Treatment options and

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explanations of therapy; Logistical issues (transportation, work, etc.); Lifestyle issues (exercise, diet, sexuality, smoking); Follow up/what happens after therapy finishes; and Support or self help groups, alternative medicine. Above these information demands, books of cancer survivors such as Lance 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 insurance company, 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 do not fit the individual 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, and therefore is 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 basis in prior related research is necessary.

Empirical Findings of Conducted Field Studies

During the European Week against Cancer (October 2002) a standardised questionnaire was distributed to approximately 500 visitors, with 116 responding. 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 mobile phones are used by 56.3% and the Internet by 43.8%. More than two third agreed in parts that

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they want to communicate more with other patients. These statements emphasise the need for web-based or mobile information and interaction services.

Additionally we conducted ethnographic analysis of self-help groups. We conducted 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 encouragement 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 travelled a long way to their self help group meetings. The use of materials and tools like mobile phones, personal digital assistants or the internet correlated 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.

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 could not be identified on a European level (German or English speaking). Only in the US were we able to find first approaches towards virtual cancer patient communities (Daum, Klein, Leimeister, & Krcmar, 2001). Existing internet services in German language offered mostly content without user interaction possibilities. Additionally hardly any services focused on quality assurance of their content or target-group specific editing of their content (e.g., most offered medical content was almost not understandable by laypeople). Concerning mobile services support for access through mobile devices, we could not identify any services in the German speaking Internet. Therefore a pilot project for developing a community platform for cancer patients was initiated.

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Requirements and the Development Process

The Dilemma of Requirements Collection

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

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

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

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Although considering many published approaches [2], we did not find an appropriate model that combined both an applicable process for the development of a platform on the internet and the inclusion of requirements engineering activities that involve intense participation of targeted users, and certainly none with a proven track record.

Requirements Deduced from Prior Field Studies

The results of prior field studies about the information and interaction needs of cancer patients (see above or Leimeister, Daum, & Krcmar, 2002) and the examination of existing web based information platforms on the German language market (see above and Daum et al., 2001) lead to the general requirements listed in Table 1.

--- Table 1 Goes About Here ---

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

A Community Platform Engineering Process (COPEP)

The objective of this section is to describe a process model for developing an information system, a community platform for cancer patients. Since system requirements are neither completely nor exactly defined, a linear model does not fit the uncertainty that arises from the field. An iterative model seems to be more appropriate. Starting out with general requirements, the system can be built step by step. The outcome of each stage of the iterative development should be evaluated. Within each iteration, however, the type of development should be shaped by the demands of the situation.

Figure 2 shows the process model COPEP (Community Platform Engineering Process) that was used during the development of the Internet platform www.krebsgemeinschaft.de for the target group of breast cancer patients.

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--- Figure 2 Goes About Here ---

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

As

Figure 2 shows, each prototype undergoes an evaluation at the end of its development cycle. That allows a high degree of involvement of target users, with experts as their representatives. The method used for evaluation was a mixture of interviews and group discussions. We presented the results of each cycle to a group of experts (iteration 1 to 3) and to a group of patients (iteration 4 and during the run of the prototype). Their feedback was integrated into the planning of the next iteration. The prototype was introduced to a broader public on August 18th 2002.

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

Design of an Online Platform for Cancer Patients

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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 (see also Leimeister et al., 2002):

- Creation of a virtual information and interaction space with appropriate communication channels according to cancer patients needs.
- Trustworthy operators (no financial interest in the subject, explicit competence in medical issues, etc.) of the community platform and transparency about the source of funds in order to support the development of trust.
- Competent content managers for the quality assurance of centrally provided content.
- Access-right structures that support the development of trust and that also support real-life situations and interactions.
- The provision of tools for working with shared material for supporting group activities that have been successfully used in computer-supported meetings.
- 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 migrate between different contexts, such as different hospitals and medical centres, work and home. Hospitals or medical professionals remain their most important source of information (Kaminski et al., 2001), but information and interaction desires are ubiquitous and are not limited to physicians' office hours. Besides that, there are other needs than just medical knowledge retrieval. 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 (Hasebrook, 1993). Opening oneself to others, dealing with very intimate and private issues requires an intimate environment. Trust could be, as always, identified as a very critical issue.

Thus we suggest (in accordance with Gryczan & Züllighoven, 1992) providing useful digital tools and digital materials for cancer patients. Tools allow modification and processing of

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material. In the tradition of Computer Supported Collaborative Work (CSCW), tools can enable users to communicate, to coordinate common tasks or to cooperate on 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, 2000). Its advantages -- from the point of view of software engineering -- lie in several aspects: It allows an intuitive handling of documents, offers easy-to-access appropriate structures, and supports existing ways of cooperation and coordination in social structures (Schwabe & Krcmar, 2000).

Three types of information and interaction spaces seem to be useful for cancer patients:

1) 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. 2) A “public room”, where all members and visitors of the virtual community can see all information and documents and search for information. 3) 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 supported 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.

Architecture and System Requirements

In order to fulfil the deduced requirements on a community-platform, a client-server-solution is utilised whose architecture consists mostly of three layers (data, application and presentation layer) (see Figure 3). This architecture allows high scalability 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 (for example XML/XSL, HTML, WML, JDBC and HTTP(S)) are supported by this system, thus permitting support for any access device using a browser (web-browser, WAP-mobile-browser, etc.).

--- Figure 3 Goes About Here ---

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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 are quite scalable. 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 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 include, for example, calendaring- or chat-modules.

In the data retention layer, information is saved permanently. The system provides interfaces which are tied into the data retention systems and which can be applied to the data storage. SQL-compatible databases 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. Thus, for example, the integration of existing data sources can be managed.

Applying COPEP: Iterative Development of www.krebsgemeinschaft.de

The following provides a summary of the development steps during each iteration with a focus on the findings from the concluding group discussions either with patients or with experts (for further details see Arnold et al., 2003).

User involvement.

COPEP counters the danger of fixating incorrect requirements during the initial phases of development by involving end users early on in the development cycle. Visualization of parts of the end product through mock-ups, scenario discussion and prototyping induce a high level of transparency. General requirements get more detailed as the development process progresses, and mistakes can be redefined. The targeted users, in our case breast cancer patients, are often unfamiliar with the use of the Internet or information systems in general. The proposed community platform was somewhat difficult for them to envision. It was also difficult for them to transfer their needs into a concrete design of a web site from scratch. Further, their fragile

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medical state prohibited prolonged and unrestricted access to them as collaborative partners. In order to meet the substantial claim of user involvement from the very beginning, representatives for the target users were substituted as consultants for the project. The role of target group representatives is to take up various positions of the system until there are mock-ups or prototypes functioning as visualization that can be presented to the intended end users. We used a group of various stakeholders as representatives (see Table 2) in order to work with as many perspectives on the system as possible.

--- Table 2 Goes About Here ---

Once the content for the platform is roughly outlined and the case scenarios are conceptualised (in our case at the end of the third iteration) the target users can more easily get involved. At this point in development, the target users are provided with the intermediate result as a basis for further design, adaptation and detailing.

Results of the First Iteration

Based on the general requirements we designed a draft of what kind of services the platform should contain. For the categorization we used the suggested composition by Brunold et al. (2000). They work with four main sections: information, communication, participation and orientation category. As seen above, the orientation category is very important since the target group is not so familiar with the use of the Internet.

--- Figure 4 Goes About Here ---

The concept (see [Figure 4](#)) was approved in the discussion by the experts. Possible services that match the needs of the patients were collected in a brainstorming session. Moreover, the evaluation lead to the requirement that the platform has to be divided into a public and a private space in order to protect users of the platform from anonymous invasion. Especially the interaction and participation services should only be usable after a previous registration and login.

Results of the Second Iteration

The work in the second iteration focuses on the design of the front end. It is made tangible for evaluation with the help of a demonstration prototype (see [Figure 5](#)). Furthermore the information section is planned in further detail and the color scheme is determined: orange, yellow and white should mediate warmth, brightness, optimism and hope.

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

Results of the Third Iteration.

The third iteration focuses on vertical supplements of the demonstration prototype. A map showing what pages are linked is the base for further development. Furthermore the communication and participation section is planned in further detail. The evaluation at the end of the third iteration produced only a few new aspects, which showed us that it was time to present the system to real users.

Results of the Fourth Iteration.

At the end of the forth iteration a runable prototype exists that is shown to end users, a group of patients who have only little knowledge of the use of the Internet. At the beginning the users kind of disassociated from the system because of their suspicion against the Internet in general. Throughout the discussion, however, they became excited about the system and had only few complaints. We implemented their recommendations to emphasize certain categories that are more important than others (emphasizing the tip from the experts in iteration two). See Figure 6.

--- Figure 6 Goes About here ---

Going Live.

A prototype for the target group breast cancer patients was introduced to a broader public on August 18th 2002. An evaluation of the running platform is currently carried out by taking into account click streams, typical behaviour of heavy users, and feedback about the design of the platform from users and experts. Based on this evaluation, the platform can be considered successful and thus COPEP has its first proven track of applicability.

As of early 2005, there are approximately 1300 registered users on the platform for breast cancer patients, with new registrations daily. Accompanying the continual refinement of the platform, an evaluation of the running platform is conducted, taking into account click streams, typical behaviour of heavy users, content analysis of the entries of the personal guest books,

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feedback about the design of the platform via email, user surveys and group discussions with cancer patients.

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

Separation into Different Areas Should Provide Transparency

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

Figure 6). This should provide transparency as to the source of the information.

--- Figure 6 Goes About Here ---

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

Private Space and Personalisation

Parts of a private room as stated above are realised within the individual welcome page. This page is only visible to the user after login (see

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Figure 7). There the user has access to his or her personal mailbox; he can modify his personal data and decide which part of the data should be visible to other community members. Beyond that, she can create a list of friends (buddy list) who have access to more of her data than the rest of the community. The possibility to give individual recommendations to other users of the community completes the service of the ‘private’ room. Recommendations could be links to other interesting web sites, addresses of good clinics, helpful literature or references to related events.

--- Figure 7 Goes About Here ---

Projected Development: Notifications and Rating possibilities

In order to encourage a more lively community and to intensify the integration of user generated content there are several projected components, including that the buddy list will be extended by a notification tool. Each time a user logs on or does a certain action on the platform, his or her buddies get a message. Another projected component is the possibility that the scientific content should be rateable by users. They will be able to comment on the user generated content as well as the centrally provided content in order to give each other or new users an orientation.

Adding Value through Mobile Services

Another promising area for the extension and improvement of virtual communities is the sector of mobile devices and mobile services. They can add value to traditional web-based communities for several reasons. They extend and/or improve already existing services.

Figure 8 visualises some possibly value-adding services.

--- Figure 8 Goes About Here ---

Through ubiquitous access to already existing web-based services, community members have the possibility to inform themselves and to interact with others at any place and at any time. 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

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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 mobile 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 new 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 take some action to request 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 such as when, how and for whom they want to be reachable. Other new services in the medical field are emergency services. It is possible to monitor parameters such as 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, such as micro-payments through 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 yet to be investigated. With the COSMOS project we hope to clarify some of the issues concerning mobile services for cancer patients.

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 outlined how a systematic design of a virtual community for cancer patients in Germany can be achieved. On the basis of in-depth field studies and with the application of an iterative development process, we have shown how requirements for

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community engineering and system development in this domain look like and what kind of components can be useful for a virtual community for patients. Mobile services have the potential to add significant value to virtual communities and especially the aspects of ubiquitous access to a community and its members and new services enabled through new mobile technologies seems very promising.

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Notes

1. The research project COSMOS (Community Online Services and Mobile Solutions) is a joint project of the Technische Universität München and O2 (Germany) GMBH & Co. OHG. The project is supported by the Ministry of Education and Research FKZ 01 HW 0107–0110. Further information can be found under <http://www.cosmos-community.org>
2. Process models for the development of community platforms in general can either be derived from existing information system development approaches (for an overview see Boehm 1989) or from community informatics works with a rather social science perspective on community (platform) building like Preece (2000) or Kim (Kim, 1999). But none of the existing approaches seems to be appropriate since they are either not detailed or feasible enough or too extensive for being manageable for smaller projects. The development of information and interaction platforms for patients in general or cancer patients in particular has special requirements that are hard to integrate in existing process models for system development.

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Table 1.

Deducted Requirements from Field Studies (Arnold, Leimeister, & Krcmar, 2003)

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

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Results/ Section	General Requirements for a Community Platform for Cancer Patients	Implications for a Process Model
	<p>Jones, 1995)). The use of colours, a constant navigation bar, larger font size and the <i>avoidance of fancy features</i> (flash-animations, mouse-over, etc) is advisable.</p> <ul style="list-style-type: none"> • Trust is a crucial element for target group, therefore access-right structures that support the development of trust and that support real-life situations and interactions are necessary (Leimeister, Ebner, & Krcmar, 2005) 	<p>is necessary.</p> <ul style="list-style-type: none"> • Process has to include access-right structures development • Process must adapt to changes of requirements during development.
Content for Platform	<ul style="list-style-type: none"> • The platform should have an <i>information section</i> as well as <i>interaction possibilities</i>. • The offered <i>information</i> must <i>be trustworthy</i> and <i>comprehensible</i> for patients. 	<ul style="list-style-type: none"> • Development process should be applicable for different types of services (information and interaction services).

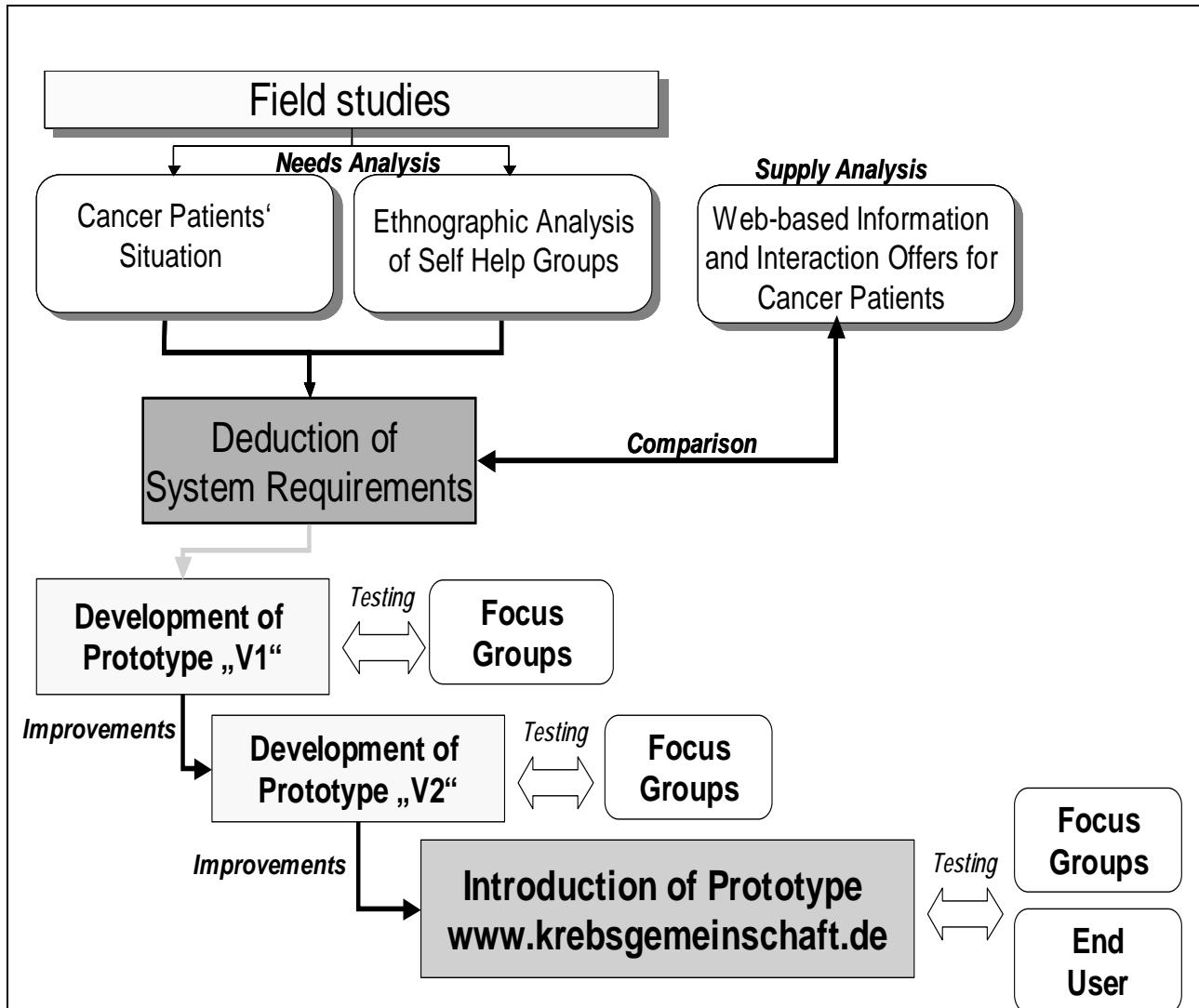
1. Leimeister, J. M.; Krcmar, H. (2006): Designing and Implementing Virtual Patient Support Communities: A German Case Study In: The Internet and health care: Theory, research and practice. Hrsg. / Editors: Murero, M.; Rice, R.E. Publisher / Verlag: Lawrence Erlbaum Associates, Erscheinungsort/ Published in: Mahwah. Erscheinungsjahr / Year: 2006.

Table 2.

Representatives during the Development

Representatives	Competence
Two Associates of a cancer patient hotline from the German Cancer Research Center (KID), Krebsinformationsdienst Heidelberg	Familiarity with cancer patients' information needs and usual questions asked Know comprehensible language for patients
One Associate of the largest German public health insurance	Familiarity with cancer patients Know-how in disease management programs
One Communication theorist	Communication theory Computer mediated communication
Two Associates of the Applied Informatics Department, Technische Universität München	Technical specification Computer programming
Two Associates of the interdisciplinary tumour centre (ITZ), Tübingen	Execution of information sessions for patients Medical know-how
Three Associates of the Information Systems Department, at the University of Hohenheim	Community engineering Human computer interaction
Two Associates of the collaborative cancer centre (OSP), Stuttgart	Execution of information sessions patients Medical know-how

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**Figure 1.**

Research Plan

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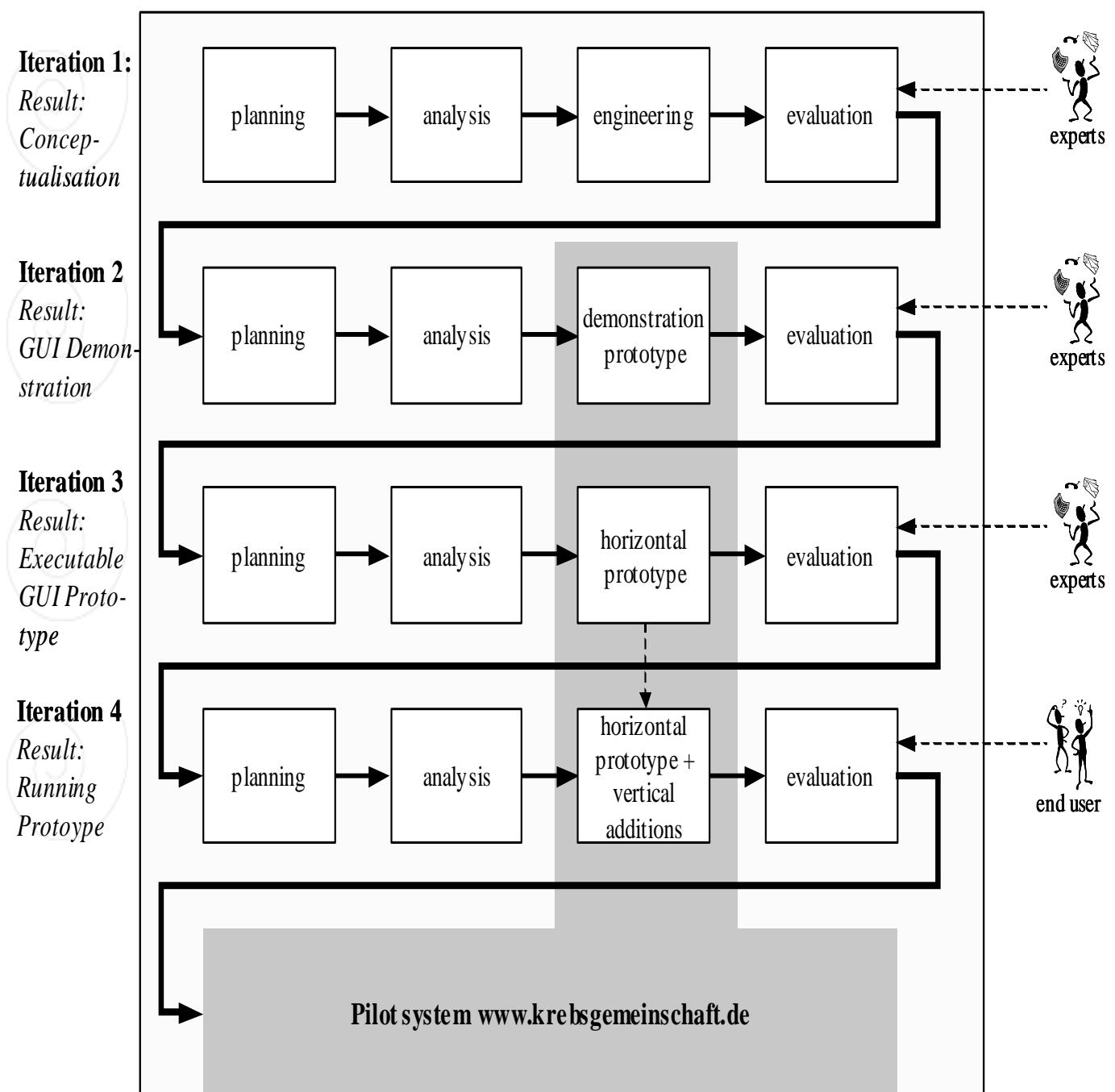


Figure 2.

Community Platform Engineering Process with 4 Iterations Combining a Spiral Model with Prototyping Elements (shaded) (Arnold et al., 2003)

1. Leimeister, J. M.; Krcmar, H. (2006): Designing and Implementing Virtual Patient Support Communities: A German Case Study In: The Internet and health care: Theory, research and practice. Hrsg. / Editors: Murero, M.; Rice, R.E. Publisher / Verlag: Lawrence Erlbaum Associates, Erscheinungsort/ Published in: Mahwah. Erscheinungsjahr / Year: 2006.

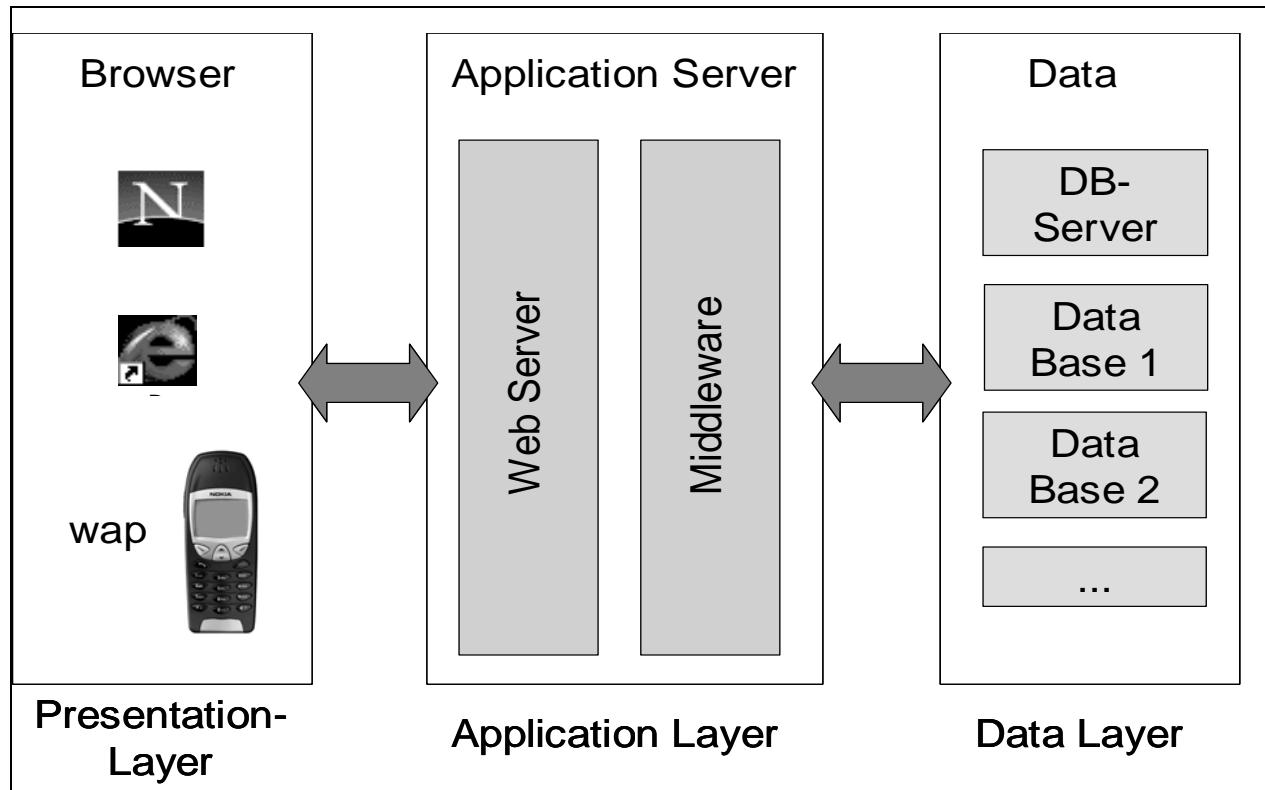


Figure 3.

Three-Layer Architecture of Community Support Systems.

1. Leimeister, J. M.; Krcmar, H. (2006): Designing and Implementing Virtual Patient Support Communities: A German Case Study In: The Internet and health care: Theory, research and practice. Hrsg. / Editors: Murero, M.; Rice, R.E. Publisher / Verlag: Lawrence Erlbaum Associates, Erscheinungsort/ Published in: Mahwah. Erscheinungsjahr / Year: 2006.

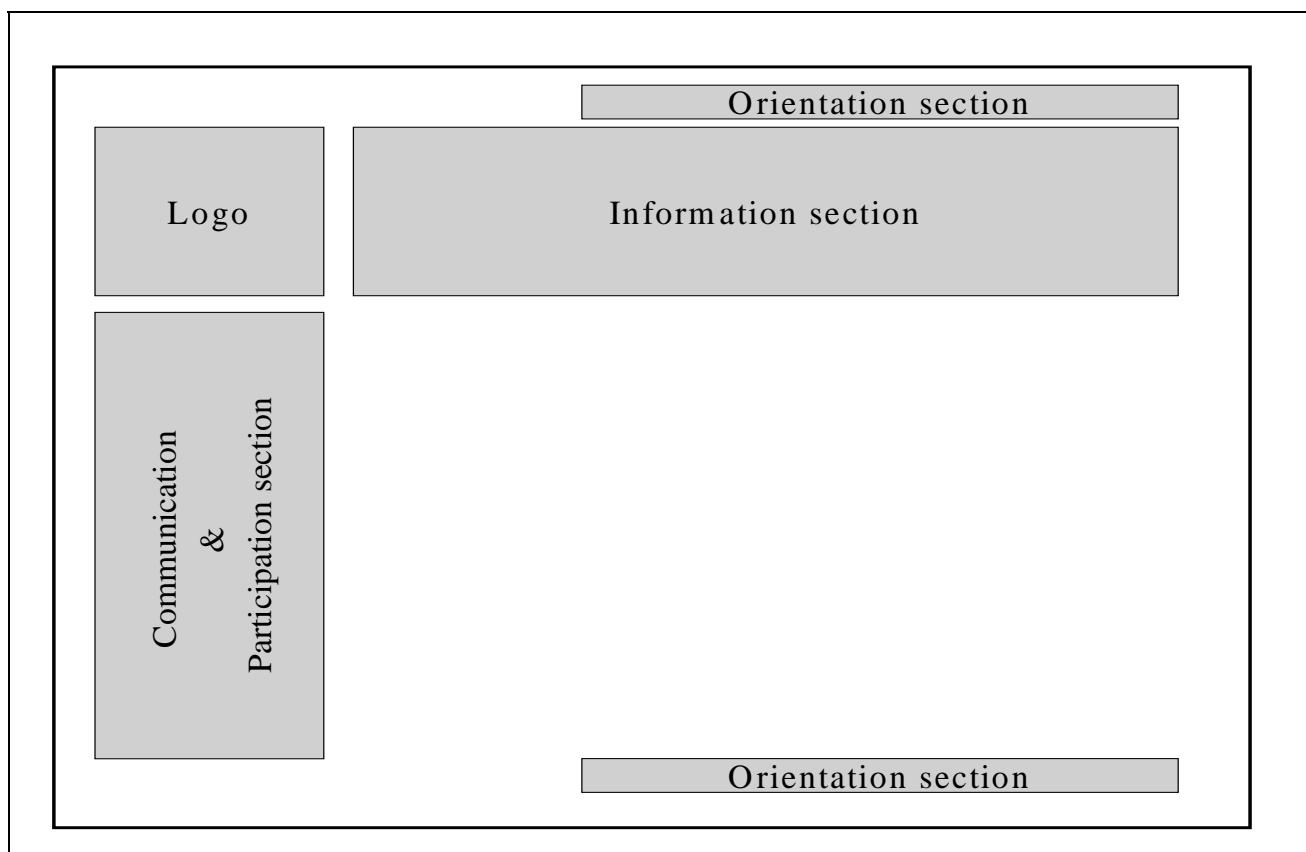


Figure 4.

Division into Sections (Arnold et al., 2003).

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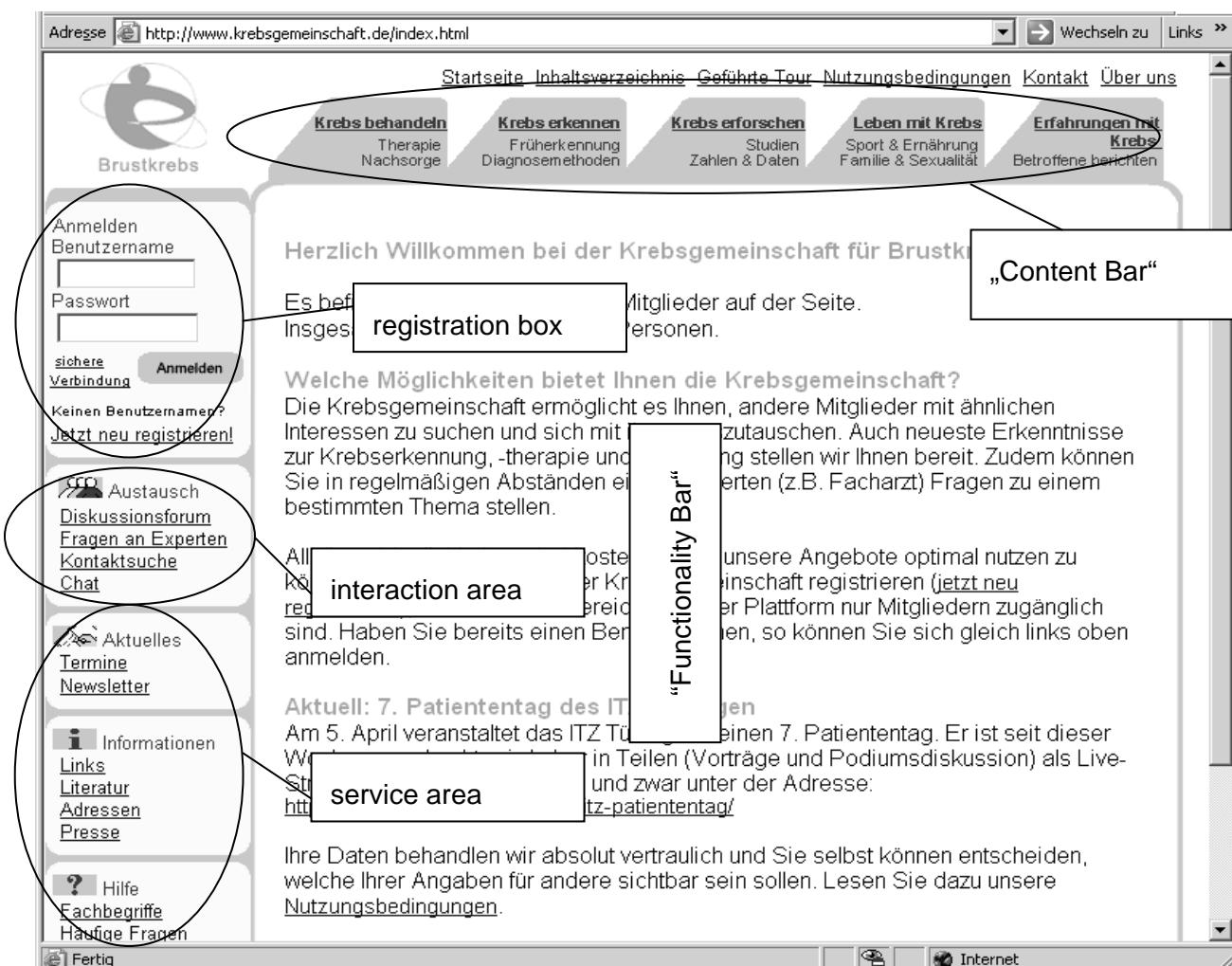
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Figure 5.

Demonstration Prototype (Arnold et al., 2003).

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**Figure 6.**

Starting Page of <http://brustkrebs.krebsgemeinschaft.de> – A Platform for Breast Cancer Patients

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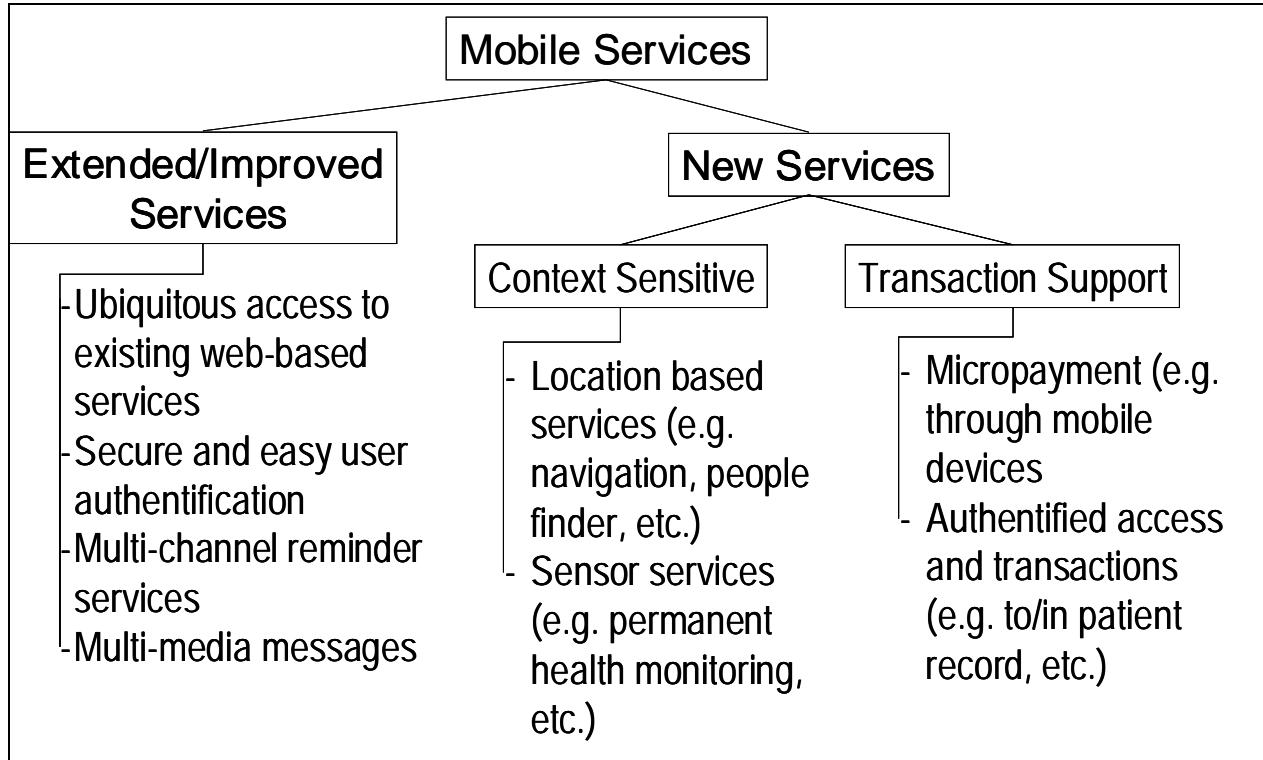
recommendation area

Figure 7.

The Personal Page of <http://www.leukaemie.krebsgemeinschaft.de> – A Platform for Leukaemia

Patients

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**Figure 8.**

Mobile Services for Adding Value to Virtual Communities

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