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CoPEP: A Development Process Model for Community Platforms for Cancer Patients

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Abstract

This paper focuses on the process of designing and implementing a community platform for cancer patients with the objective to derive a process model for community engineering. Following an introduction to the situation of cancer patients in Germany we summarize our findings on cancer patients' demands for trustworthy information as well as their need for interaction with peers in similar situations. On this basis we describe the process of translating socio-technical needs into system requirements and the steps undertaken to develop a functioning community platform for cancer patients. We combine a generic iterative process model for systems' development with elements of prototyping towards an engineering process model for community platforms for cancer patients. The paper focuses on specialised situations and challenges concerning user interface development and system requirements' analysis taken into account during system development.

Keywords

Community engineering, web-based system development, process model, user involvement, requirement engineering, website design, cancer patients, healthcare

1 Introduction¹

Community platforms on the Internet have great potential to serve ubiquitous information and interaction needs. Such an omnipresent demand exists, for instance, in healthcare when patients develop a desire for information and supportive communication which exceeds what is offered by either the treating physician and/or health care institutions.

1.1 Cancer and the Healthcare System in Germany

The number of new cancer incidents in Germany sums up to 164900 male and 173400 female cases per year (AG Krebs 1999). According to the report of the National Advisory Council to the German Government (Gesundheitswesen 2001) the treatment of cancer patients in Germany is often not efficient. The relationship between physician and patient is often described as being paternalistic. A situation which does not lend itself to patient participation in decision-making. In order to obtain quality care and the appropriate treatment in today's complicated health care system, patients must be active and competent consumers. Suitable information available at the right time is crucial in aiding decision-making. "Recent surveys show that 40-54% of patients access medical information via the internet and that this information effects their choice of treatment" (Meric et al. 2002). Medical information is not all that is needed or sought on the internet. "E-Health offers patients databases of medical information, but patients want to hear about treatments and how to deal with problems from other patients" (Preece 2000, xvi).

1.2 Cancer Patients' Needs for Information and Interaction

Patients' needs and demands for information often increase after a diagnosis of a disease or during medical treatment (Sheppherd et al. 1999). Patients seek information in order to help them make sense of a given diagnosis or to assist them in making decisions about treatment. In addition to demands for factual information, patients seek emotional support and the opportunity to communicate with other patients experiencing similar physical and emotional symptoms. The need for information and interaction plays an important role in dealing emotionally with a disease, an assumption backed by research on self help groups (for an overview see e.g. Hasebrook 1993). The diversity of over 100 types of cancer, the complexity of treatment modalities coupled with hardly manageable professional and lay literature makes coping with the informational, emotional and medical aspects of cancer extremely difficult and tiresome. The evolution of virtual communities has been a positive step in meeting the emotional and educational needs of cancer patients without overtaxing their already limited physical and psychological resources.

Designing and building virtual communities has been the focus of science and practice for a number of years (for an overview see e.g. Schoberth 2003). However there is a paucity of empirically tested process models for the development of community platforms in general and the healthcare sector specifically. Following is a description of the first steps taken towards creating a process model for developing community platforms in healthcare.

¹ This paper resulted from of the research project COSMOS (Community Online Services and Mobile Solutions). COSMOS is a joint research project of the Hohenheim University, the Technical University Munich, Ericsson Deutschland GmbH and O2 (Viag Interkom GmbH & Co). The project is funded by the German Ministry of Research and Education. For further information please visit the website: <http://www.cosmos-community.org>.

2 Requirements Engineering and the Development of Community Platforms

2.1 The Dilemma of the 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. Orphaned community platforms on the internet underline this mismatch. 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. Alternative models have been developed as the linear model contains many dysfunctional aspects (for an overview see Balzert 1998, for further critics see e.g. Boehm 1989). The internet as a possible environment for an information system targeted to heterogeneous user groups demands more flexibility and, at the same time, has a high degree of uncertainty.

In 1995, the European Software Process Improvement Training Initiative (ESPITI) surveyed problems within the software engineering process. The two most commonly identified problems were ‘requirements specification’ and ‘managing customer requirements’ (see Leffingwell/Widrig 2000, 8). According to Conallen (2000, 89) requirements is defined as “a statement of what the system should do. The collection of all of the requirements of the system is the requirements specification”. The collection of requirements takes place 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 later phases of development. Therefore, it is essential to pay particular attention to the collection and adaptation of requirements and to involve the target user in early stages of the software development cycle. The requirements engineering approach attempts to take into account these key elements. 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, 17). This definition incorporates the understanding that requirements can (and do) change during the development process.

In order to develop a platform that meets users’ needs, requirements engineering addresses essential success factors for system development; it is therefore, a suitable framework for the development of a community platform. Numerous activities and methods reported in the literature guide and support the discovery of requirements (for an overview see e.g. Hofmann 2000). The questions remain, are they applicable for our purpose and can they be combined with a process model for system development?

Following an extensive review and consideration of published approaches², we were unable to secure an appropriate model that combined an applicable process for the development of a platform especially for the Web (for a discussion of Web Engineering see also Murugesan et al. 1999 and Gaedke & Gräf 2000) and the inclusion of requirements engineering activities that involve intense participation of targeted users.

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 e.g. Boehm 1989) or from community informatics works with a rather social science perspective on community (platform) building like Preece (2001) or Kim (1997). None of the existing approaches seems to be appropriate as 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 difficult to integrate in existing process models for system development.

2.2 Requirements deducted from prior Field Studies

Prior field studies pertaining to the information and interaction needs of cancer patients (see also Leimeister et al. 2002) and the examination of existing web information platforms on the German language market (Daum et al. 2001) lead to the following general requirements:

Results/ Section	General requirements for a community platform for cancer patients	Implications for a process model
<i>Development of platform</i>	<ul style="list-style-type: none"> The envisioned community platform is an innovation. No comparable system exists on the German speaking internet (none offers interaction possibilities). Therefore all the requirements cannot be collected in advance 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 a flexible design of the front end. Aspects such as size of screen, supported types of browsers and transfer rates must be taken into consideration within the development process. 	<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.
<i>Target group</i>	<ul style="list-style-type: none"> The navigation of the platform should be intuitive as most cancer patients are older and unfamiliar with the use of the internet (for similar findings see e.g. Binsted et al. 1995). The use of colours, a constant navigation bar, larger font size and the avoidance of fancy features (flash-animations, mouse-over, etc) is advisable. 	<ul style="list-style-type: none"> Use of mock-ups and prototypes for demonstration purposes is necessary. Process must adapt to changes of requirements during development.
<i>Content for platform</i>	<ul style="list-style-type: none"> The platform should have an information section as well as interaction possibilities. The offered information must be trustworthy and comprehensible for patients. 	<ul style="list-style-type: none"> Development process should be applicable for different types of services (information and interaction services).

Table 1: Deducted requirements

Starting out with these general requirements, the process model has to integrate parallel activities of requirements engineering to provide the flexibility needed for the development of a web based platform. Therefore an applicable process model should:

- be an iterative process,
- be able to adapt to changes of requirements during the development process,
- include several mock-ups and prototypes,
- be easy to apply especially for small and medium size projects,
- be applicable for different types of services (information as well as interaction),
- involve users from the beginning.

In the following we suggest a process model that meets these preconditions.

2.3 Towards a Community Platform Engineering Process (CoPEP)

The heart of the following process model is an iterative process adapted from the generic spiral process model (Boehm 1989, 26 and Wigand 1998). It is combined with elements of prototyping. In opposition to the original spiral model, a stronger focus is placed on scenario discussions, the display of mock-ups and prototypes, and the active involvement of users. Requirements are collected and adapted within each iteration. Figure 1 shows the process model CoPEP (Community Platform Engineering Process) that was used during the development of the platform www.krebsgemeinschaft.de for breast cancer patients.

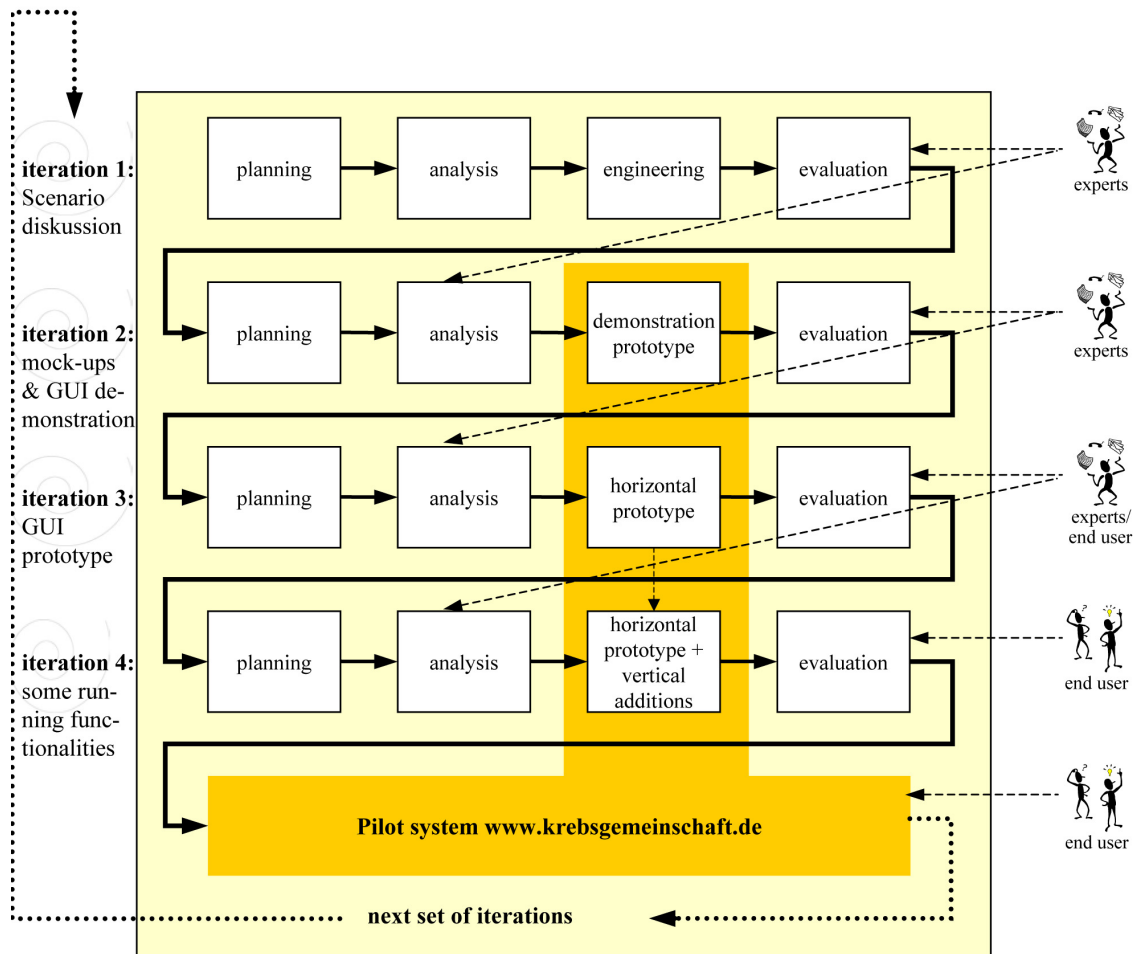


Figure 1: Community Platform Engineering Process (CoPEP) combining a spiral model (light yellow) with prototyping (dark orange)

Beginning with the planning phase, the activities for the respective iterations are scheduled. Afterwards the needed input for the tasks is analysed and the appropriate requirements are either deduced from the prior field studies (iteration 1) or simultaneously collected through user involvement (iteration 2-4). The rendered part of the system is evaluated after the engineering phase is completed. Using the deduced general requirements (see chapter 2.2), the translation of the socio-technical needs into system design is done iteration by iteration with the assistance of users. After cycling through the phases a total of four times, the pilot system was operative and could be introduced to the broader public on the internet on August 18th

2002. System development, however, doesn't cease with the launch of the platform. A Web Platform is a dynamic system; the demands of the users continuously change and therefore the requirements change with usage. Continual refinement is necessary (see also Murugesan et al. 1999). With the launch of the system begins the next set of iterations. Enhancements and supplements to existing functionalities are discussed in scenarios and iteratively added onto the system following the CoPEP-model.

2.4 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 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 (for similar findings see e.g. Forsythe 1992). The role of target group representatives is to take up various positions upon 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 (for the role of multiple perspectives within system development see e.g. Floyd, 1992).

<i>Representatives</i>	<i>Competence</i>
Associates of a cancer patient hotline (KID), Krebsinformationsdienst Heidelberg	<ul style="list-style-type: none"> • Familiarity with cancer patients information needs and usual questions asked. • Know comprehensible language for patients.
Associate of the largest German public health insurance	<ul style="list-style-type: none"> • Familiarity with cancer patients. • Know-how in disease management programs.
Communication theorist	<ul style="list-style-type: none"> • Communication theory. • Computer mediated communication.
Associates of the Applied Informatics Department, Technische Universität München	<ul style="list-style-type: none"> • Technical specification • Computer Programming
Associates of the interdisciplinary tumour centre (ITZ), Tübingen	<ul style="list-style-type: none"> • Execution of information sessions for patients • Medical know-how
Associates of the Information Systems Department, at the University of Hohenheim	<ul style="list-style-type: none"> • Community Engineering • Human Computer Interaction
Associates of the collaborative cancer centre, Stuttgart	<ul style="list-style-type: none"> • Execution of information sessions patients • Medical know-how

Table 2: Group of Representatives

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 confronted with the intermediate result as a basis for further design, adaptation and detailing.

3 Applying CoPEP: Iterative Development of www.krebsgemeinschaft.de

In the following, an excursion of the work during each iteration with a focus on the findings from the group discussions in the analysis and evaluation phase is presented (for further details see Arnold 2002).

3.1 Results of the first Iteration

Starting from the general requirements, we identified four groups of content to be presented on the platform: information, orientation, communication & participation. A scenario discussion with the group of experts during the analysis phase (see table 2) located potential problems with the navigation of the content. Furthermore, the importance of identifying and segregating scientific and user generated content was identified as patients are probably not aware of the difference between facts and opinions. A solution was agreed upon: meta information (author, date of creation, status etc.) should provide transparency as to the source of the information. For the end user the difference should be transparent by the placement of the sections (see figure 2), some meta information should also be visible on the presentation layer.

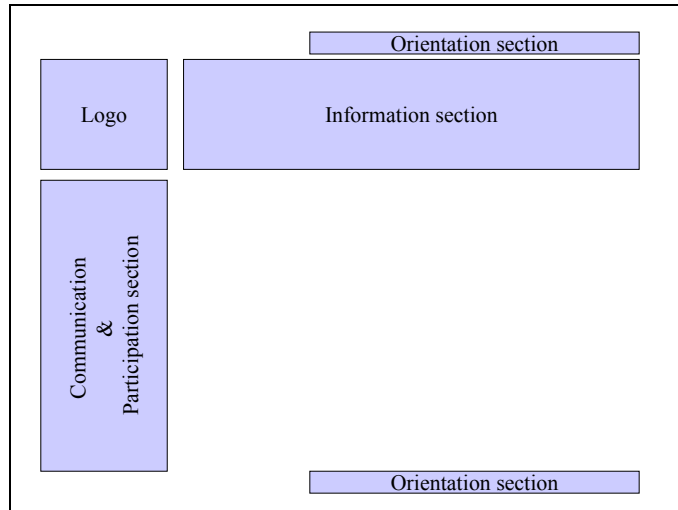


Figure 2: Division into sections

The results of the engineering phase was made visible with the use of mock-ups that were presented for evaluation. Following group discussion, it was agreed that some content should be restricted and accessible to users that are registered. Associates in the project with familiarity with cancer patients insisted on content that can be accessed without a login as there are many patients who are sceptical to provide personal information. This feeling is backed by community research which shows that a greater part of community members are lurkers (see Nonnecke/Preece 2001, 1528). It was decided that only the interaction and participation services would be accessible following registration and login.

3.2 Results of the second Iteration

The work in the second iteration focuses on the design of the front end. The information section is planned in further detail and the colour spectrum is determined: orange, yellow and white should mediate warmth, brightness, optimism and hope. According to the reading habits of web users and the distribution of attention on web sites, subcategories within the sections are placed.

The evaluation workshop with the group of target group representatives consisted of a rating of the colours and the designed categories based on a demonstration prototype of the user interface. Brainstorming sessions took place to determine what type of communication services best fits the needs of breast cancer patients. High priority was given to services that possibly provide displays of empathy such as experience reports, personal guest books or topic categories on 'how to deal with cancer'.

3.3 Results of the third Iteration

The third iteration focuses on vertical supplements of the demonstration prototype. The analysis identified what type of services and content should be linked and which group should have access to the various sections. A navigation map showing the results provides the basis for further development. During the third iteration the communication and participation section was constructed in further detail. As trust is a crucial element for the target group, access-right structures that support the development of trust and depict real-life situations and interactions are necessary.

A prototype of parts of the whole system was constructed and served as a basis for the evaluation at the end of the third iteration. Various scenarios are used to illustrate the technical design of access-right structures. There are different types of users: a normal user, a super user, a community manager and an administrator. These roles were considered as practicable by the representatives. The subsequent discussion produced few new aspects which showed us that it was time to go a step further and present the system to real users.

3.4 Results of the fourth Iteration

The goal of the fourth iteration was to have a rough outline of a prototype running that could be shown to end users in a group discussion session. We invited a group of breast cancer patients (average age 58) who had little knowledge of the use of the internet. At the beginning, the users were sceptical of the system because of their general mistrust of the internet. We presented the various sections of the system and asked them to rate the functionalities. Furthermore we fostered a peer to peer discussion. Throughout the discussion, the group became more excited about the system and found few faults. Through this exercise, we gained deeper insight into how to present information and interaction services on the platform. The groups' proposals and impulses were implemented in the engineering phase.

3.5 Going Live after the fourth Iteration – the next Set of Iterations begins

A prototype for the target group breast cancer patients was introduced to a broader public on August 18th 2002 (see figure 3).

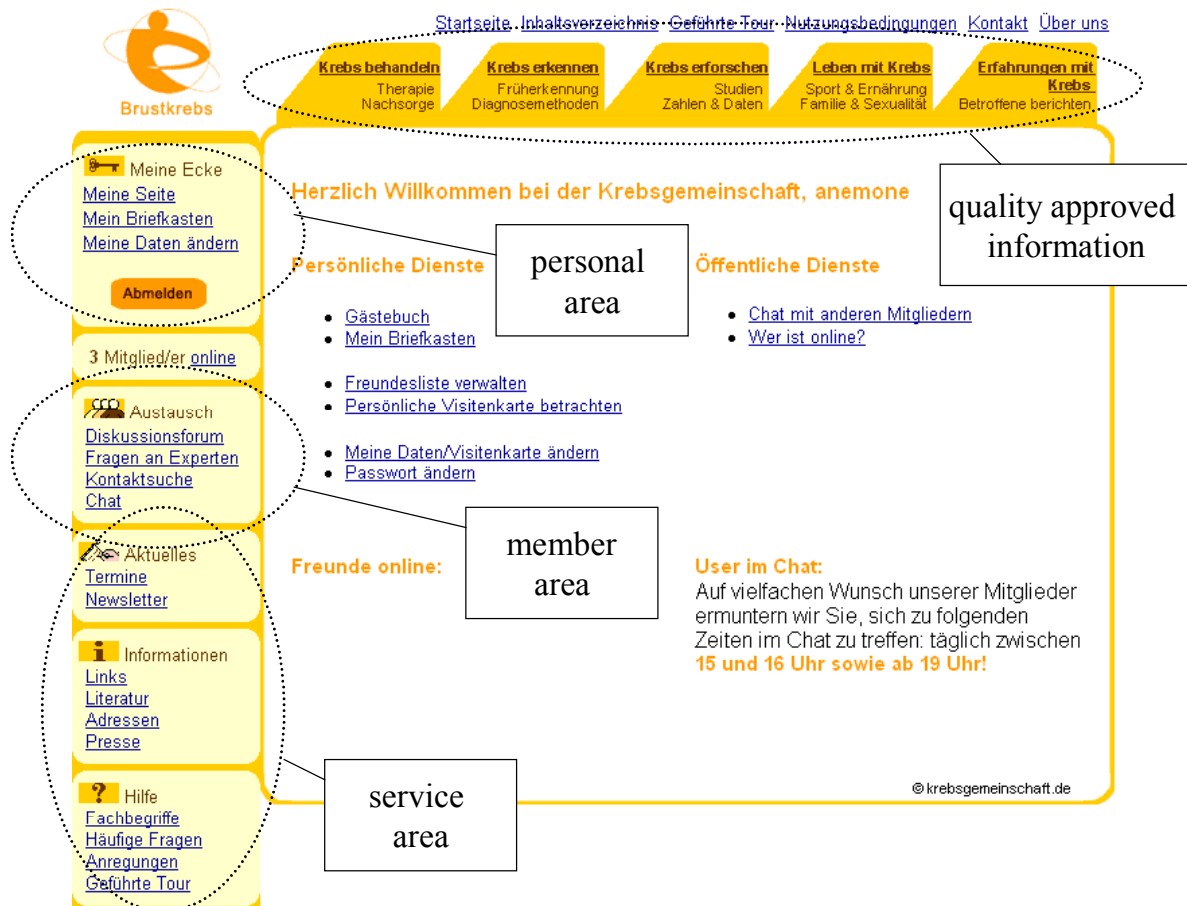


Figure 3: The pilot system www.krebsgemeinschaft.de for breast cancer patients.

At present, there are approximately 600 registered users on the platform 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 as well as a collection of feedback to the design of the platform via email, user surveys and group discussions with cancer patients. Due to the usage numbers of the platform and the feedback provided from users and experts, the platform can be considered successful and thus CoPEP has its first proven track of applicability.

4 Preliminary Results– Lessons learned from the Use of CoPEP

Better and more concrete results were achieved through the use of visualization methods (mock-ups, prototypes or scenario discussions) during the analysis and evaluation phases of the development. Visualisation allowed the participants (especially the targeted users) to better comprehend the concept and therefore indicate to us possible problems to be solved.

The communication structure continuously changed during the development phases. Each involved group had their “own language” which caused difficulties in communication. Starting with a ‘many to many’ communication behaviour, after a while the interaction involved one or two individuals who functioned as intermediaries between the content supplier, the

graphic designer, the representatives and the technical staff. We recommend that each development team contain at least one person who assumes the role of intermediary.

Although there was an ongoing discussion and sound rating of the benefit of a chat service on the platform, the actual usage of this functionality was a surprise for the development team. What happened? The scenario analysis and rating resulted in a low score for the chat room as the experts indicated that elderly women would be reluctant to use this form of personal communication via the internet. The patients themselves indicated that they would rather use the telephone for synchronous communication. The pilot system offered a sparse version of a chat. However, over time we registered a growing usage of the chat. Patients started to realise the advantages and finally asked during a feedback session for an upgrading of the functionality and a larger window so that more people could take part in a chat session. This example demonstrates that continuous user involvement and feedback cycles as proposed with CoPEP are of great importance in keeping up with the adaptation of requirements.

The approach of the study, to first gain an overview of the available offerings and the needs of the target group through field studies and then derive rough requirements for the design and functionalities was a good strategy. The successful launch of the prototype in August finally shows that the chosen process model, CoPEP, with its emphasis on requirements engineering work through intense use of mock-ups, prototypes and scenario discussions with target users and experts of the domain is working.

5 Outlook for further Research

By the time of the conference, we hope to be able to present further experiences with the use of the CoPEP-model. We are currently working on the development of a platform for a second target group (leukaemia patients) and on the development of mobile device interfaces that extend the existing community platform for breast cancer patients.

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