VIRTUAL COMMUNITIES IN HEALTH CARE: ROLES, REQUIREMENTS AND RESTRICTIONS

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ABSTRACT

Community platforms on the Internet have the great potential to serve ubiquitous information and interaction needs. This applies especially in the health care domain, where the need for information and interaction is ubiquitous as well as often spontaneous and of a long term nature. The potential users are from all levels of society and therefore have different experience with the usage of the medium Internet. But there are no recommended actions how to develop and maintain a community for patients in the health care domain. Instead there are several challenges that need to be met throughout the development and maintenance of a platform in such a domain. So as to achieve the greatest congruency between the patients' needs and the services of the platform both the potential users needed to get involved into the development process and a sound evaluation of the conceptualised product is necessary. Furthermore the offered information must be quality assured. Taking this into account, we conceptualised and implemented a community platform www.krebsgemeinschaft.de for breast cancer and leukaemia patients, their relatives and anyone interested in information about cancer. The article gives an overview of the used methods and focuses on the specialties in the health care domain.

KEYWORDS

Health care community, community engineering, community evaluation, web based community

1. INTRODUCTION – EXISTING NEEDS FOR A CANCER PLATFORM

"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). Community platforms on the Internet can fulfil this need. Especially in health care when patients develop a desire for information and supportive communication outside of the physicians office. But a study of already existing offers for cancer patients on the German speaking Internet showed that only a few websites for cancer patients offer interaction possibilities, a prerequisite for a virtual community. In 2001 there was none (Daum et al. 2001, p. 13ff) and in 2002 there were only 18% (Daum and Krcmar 2002, p. 9) of a total of 268 scanned web sites.

There is a multiplicity of literature about recommended actions for community engineering (e.g. Preece 2000; Kim 2000; Stegbauer 2001 and Bullinger 2001) but non is available that deals especially with the requirements in the health care domain. This is the starting point for the development of

krebsgemeinschaft.de[1] – an online platform for breast cancer and leukaemia patients, their relatives and anyone interested in information about cancer. The following questions are of particular interest for us and will be answered by this article:

- What does a development process model look like that succeeds in letting the target group participate within the development process in order to make sure that the end product is matching the needs of the patients?
- Which methods can be used to evaluate whether the created platform is satisfying the patients` needs?
- How can we differentiate our service from other information and interaction services which are not quality approved or of intransparent character?
- Are there any specific roles on the platform that are unique to the health care domain and how to deal with online counselling?

In the following chapters we give an overview of the used development process CoPEP, the services offered on the platform and the evaluation framework. Subsequently we describe the community roles, the quality assurance and the handling of the legal restriction existing in the health care domain.

2. COPEP – A COMMUNITY PLATFORM ENGINEERING PROCESS

In order to meet the substantial claim of user involvement from the very beginning, we used the CoPEP process model (for further details see Arnold et al. 2003). It combines an iterative process adapted from the generic spiral process model (Boehm 1989, p. 26; Wigand 1998) with elements of prototyping (see figure 1). 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.
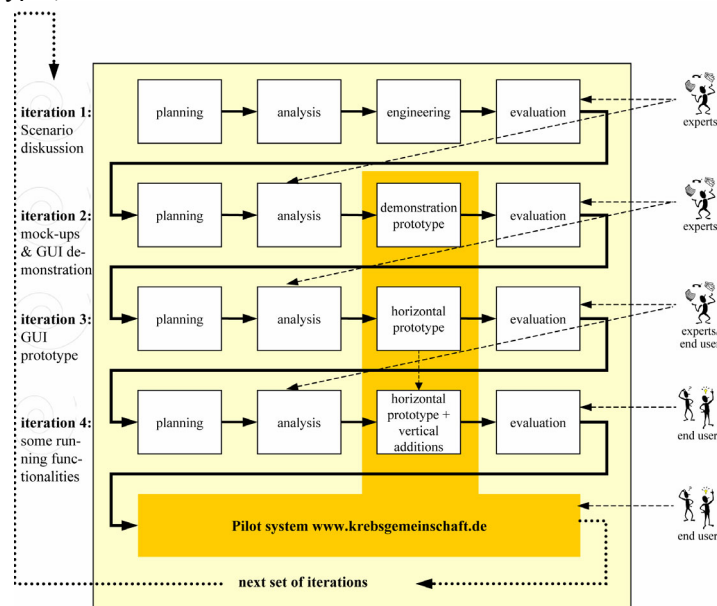

Figure 1. Community Platform Engineering Process (CoPEP) combining a spiral model (light gray) with prototyping (dark gray) (see Arnold et al. 2003)

Requirements are collected and adapted within each iteration in a group discussion. In order not to overstrain the patients because of their sometimes fragile medical state, their participation was substituted by representatives 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

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functioning as visualization that can be presented to the intended end users. We used a group of various stakeholders to gain as many perspectives on the system as possible (for the role of multiple perspectives within system development see e.g. Floyd 1992): associates of a cancer patient hotline in Heidelberg, associates of the largest German public health insurance, a Communication Theorist, associates of the Applied Informatics Department of the Technical University Munich, associates of the Interdisciplinary Tumour Centre Tübingen, associates of the Information Systems Department at the University of Hohenheim and associates of the collaborative cancer centre in Stuttgart. After cycling through the phases four times, the pilot system was operative and introduced to the broader public on the internet on August 18th, 2002. The platform www.krebsgemeinschaft.de consists of both, quality assured content and interaction possibilities where members can discuss topics and ask questions (see figure 2). The personal space with a personal email box, guest book, buddy-list and the particular personal data can only be accessed and be seen after login.
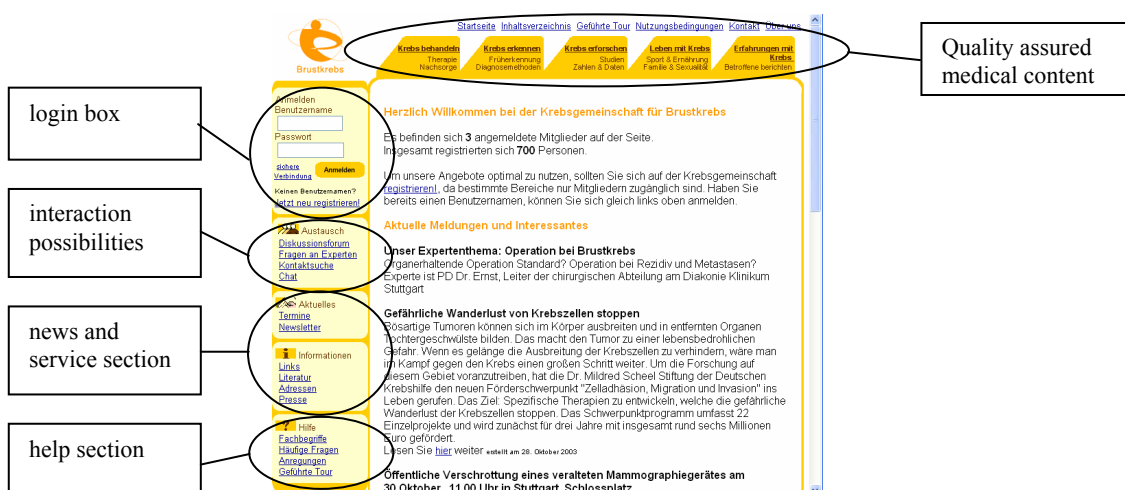

Figure 2. Homepage of the platform www.krebsgemeinschaft.de, accessed on Oktober, 29th 2003

System development, however, does not cease with the launch of the platform. A web platform is a dynamic system; demands of the users continuously change and therefore the requirements change with usage. Continual refinement is necessary (see also Murugesan et al. 1999). For example we were asked to prolong the cycle of the ask-the-expert forum. Originally the theme should change every two weeks but the users weren't fast enough in asking questions resp. it always takes a while until the theme is well-established and the users start asking questions. Another request of the users was to enlarge the chat window so that more users can participate at a time. This is the point where the evaluation comes into play. With the launch of the platform the next set of iterations started but then with a strong focus on the evaluation of the implemented services and on the adaptation. In the following we describe the used evaluation framework.

3. EVALUATION

There is not much literature about the evaluation of health care communities yet. In the financial sector there is a study about a virtual community; literature for communication activity in communities could also be found (see Schoberth et al. 2003; Butler 2001; Whittaker et al. 1998; Jones and Rafaeli 1999). Therefore our experiences during the development, introduction and maintenance of krebsgemeinschaft.de can give valuable insights for community engineering in same or similar domains. The evaluation is needed to adapt the platform continuously to the members needs.

3.1 Evaluation framework

With the help of evaluation methods we are able to discover what kind of services are used most often by our target group or whether the community fulfils the needs described in literature as well as found out in our

prior field studies. For our evaluation we relate to Schwabe's evaluation model (2000, p. 240ff): the evaluation can take place at several levels: management of introduction, usage and work of the municipal council. In our case the third level is not of interest, instead it is substituted by the level 'individual information and interaction behaviour' (see also table 1). Subsequent the evaluation model is described in brief. On the level *management of introduction* it is important that our platform reaches cancer patients, our potential users. Only then is it used and only then can there be changes in the information seeking and interaction behaviour of the patients. Furthermore all factors that influence the platform need to be considered. The activities of all involved people are written down daily in excel sheets for further analyses, e.g. events like trainings of patients, establishments of computers in our partner hospitals, news items, mailings of flyers, etc. If the management of introduction is successful it leads to the *usage* of the virtual community. There, the following data is of special interest: number of members, kind of persons (patients, friends, etc.), time, duration and frequency of usage, activity on the platform as well as what kind of services are used. Based on these findings, conclusions of certain user groups can be drawn. For example there could be relations between gender, status of disease, education/literacy, time of membership and the usage of krebsgemeinschaft.de. For the evaluation of the *information and interaction behaviour* we use a 5x4 matrix with the categories: costs, time, quality, flexibility and human situation and the levels working place, process, organisation and group (for evaluation models see also Reichwald et al. 1998 and Schwabe 2000, p. 240ff).

3.2 Object and methods of evaluation

In the following we describe what kind of data collection methods we used for the management of introduction, usage and information and interaction behaviour (see also table 1). If possible so far research findings are described. At the time of the conference we will be able to present newer data.

Table 1. Levels of evaluation and data collection methods

data collection levels	survey/ questionnaires	obser-vation	analyses of documents	log files	group discussion
management of introduction	x	x	-	-	x
usage	x	-	x	x	x
information and interaction behaviour		-	x	x	-

During the introduction phase we distributed a **questionnaire** at the "European week against cancer" and in self-help-groups. The first questionnaire was answered by 116 people (return rate 23%). 37% of the women and 31% of men agreed that they want to look for information on the Internet. 29% of these women and 44% of men did use the Internet already. 44% of men and 29% of women wanted to communicate more with other patients (see also Leimeister et al. 2002). The results confirmed findings that the majority of cancer patients has a strong need for information and interaction possibilities with other patients. Our first online questionnaire in June 2003 with the topic trust was answered by n=32 registered users of our breast cancer community. The majority (59%) was under treatment, 90% of the patients had no metastasis. 50% had already been members of the community for more than 6 months at a time when the community was online since ten months. The results show that the possibility to communicate with other patients online is an important thing and an advantage against traditional offers within the healthcare section.

The **observation** on the level management of introduction took place in self-help groups and confirmed our findings of the questionnaires. The majority of self-help group members found it important to exchange information with other patients and to stay in contact with them. They get hope and confidence when another member is on the way of recovery. Furthermore information about different therapies and alternative treatment is exchanged as well as personal problems. We identified the existence of different roles in these groups which we used for the conceptualisation of similar roles on the community platform: There are different roles and an anonymity concept (see also Ebner et al. 2004).

The **analysis of documents** has been used on the levels usage and on the level information and interaction behaviour. An analysis of postings on the discussion board in February 2003 showed that we had 85 threads on our discussion board with an average of 3 answers and about 90 answered questions by our experts (number of registered users n= 500). The answers vary between 0 and more then 10. It can be stated

that emotional topics like fear or hair loss receive more answers then general statements about an event or medical topics. This might be because most of the medical information needs are covered by our quality assured content provided by our partners that have a long time experience about cancer patients needs.

The analysis of the guest books carried out interesting results (see figure 3). The individual guest book is displayed together with the business card on each one's page. In May 2003 there were 634 guest books on the platform. Thereof 273 members have chosen not to show any data on their business card except their user name. These members together received only 30 postings in their guest books. 281 out of 634 members displayed their personal data on the anonymous level and received together 220 postings. Only 80 members are displaying all of their personal data on their business card but together they had 383 postings, what is quite a lot. And a few, very active members had more than 50 postings in their guest book.
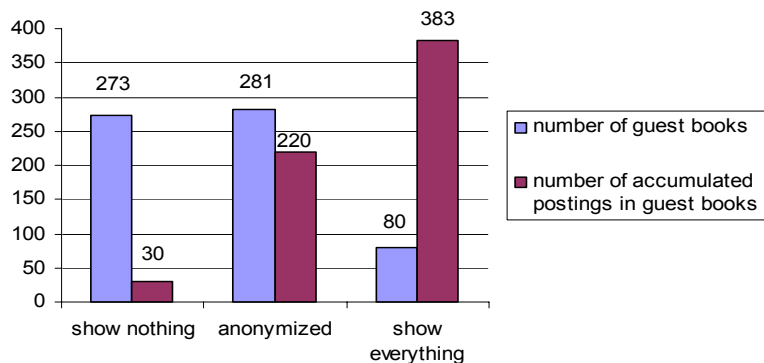

Figure 3. Guest book postings and status of anonymity

Log files are being recorded during usage and for the analysis of the information and interaction behaviour. We are currently evaluating the results and will be able to present more data at the time of the conference. In advance we can give some figures from the first 6 months online of our breast cancer community. The page used most often was naturally the start page (31%), followed by the discussion board (8%) and information about treatment (4%). The categories living with cancer, meet the expert, experiences with cancer, cancer indication, guided tour and help followed with 3%.

We use the method of **group discussions** at every level of evaluation. A group discussion or focus group session offers the possibility to gain a deeper insight into the type of requirements and reasons for usage of the target group. This means the usability of the community and the expected interaction modules can be tested in an almost real environment. In the very beginning the goal of these sessions has been to collect some requirements. After having developed a running prototype, we conducted another two sessions. This time the goal has already been shifted more towards the evaluation especially because we registered that requirements change during usage. E.g. the chat service got a low score in the group discussions, however, over time we registered a growing usage of the chat on the platform itself. User asked for a bigger window so that more users would be able to take part simultaneously. This example demonstrates that continuous user involvement and feedback cycles as proposed as well as a combination of various evaluation methods are of great importance in keeping up with the adaptation of requirements.

4. ROLES, QUALITY ASSURANCE AND LEGAL RESTRICTIONS

4.1 Concept of roles on the platform

On the platform www.krebsgemeinschaft.de there is a special role concept consisting of a guest, a member, a super user, an expert, a content manager and a community manager role. This construct is needed in the health care domain for several reasons (see also chapter 4.2 and 4.3). The rights increase on each level.

Anonymous surfers without registration have the guest status. They can access the content of the tabs and are able to read the postings on the discussion board. But only a member (a registered user) is also allowed to

answer threads in order to prevent misuse or spamming by anonymous people (for disinhibition through anonymity see also Döring 1999, p.214-216).

The role of the super user has not yet been fully implemented. The driving idea for this concept has been the fact that many cancer patients initiate a self-help group or post their experience on their personal homepages in order to help other patients. Krebsgemeinschaft.de will provide a virtual space to the super user for their commitment. As a super user they could set up an own chat room, give newcomers advice how to deal with the navigation on the platform etc. This status can be compared to a self-help group leader in real life. The super user could introduce new members to the platform (like a partnership) and help them in case of problems.

Originally the expert status is the only status with the right to answer questions asked by the members on the ask-the-expert board. In the meantime the community manager is mediating between the experts and the ask-the-expert board because there has been several problems with the quality of the answers and the skill of the experts to use the Internet (see also chapter 4.3).

On many platforms there is one community manager who is responsible for both the content and the moderation. For quality assurance reasons we have split this responsibility. There is a content and a community manager. The duty of the content manager is to provide and revise the quality assured medical content (after an editorial process) in a manner that the users can understand it. Besides that a content manager takes care of the actuality of posted events, literature tips and addresses etc.. The outcome is that our content consists of hard facts without any opinion interfering.

The community manager instead moderates the discussion board, recruits experts, administers the feedback of users, writes newsletters and keeps an eye on possible advertising of pharmaceutical companies. He has the right to comment and if necessary (e.g. if a posting contravenes the guidelines and terms of use) to delete a posting. He is kind of a mediator between the patients interest in counselling and individual solution of the patients problem and the restriction that there is no virtual counselling allowed in Germany. On the strength of past experiences we can identify two challenges the community management is faced with: first it is difficult to recruit the experts (who participate voluntarily and without payment). Many of them represent the part of doctors who still think that the choice of treatment is made by the doctor alone without any participation of the patient. Others are not accustomed to the Internet as a means to communicate with patients or to the use of the medium itself. Second challenge is the monitoring of the answers of the experts for congruency with the guidelines of quality assurance.

Conclusion: If the community manager does a good job, that is to recruit competent experts, to moderate the forum in a way that he fosters the interaction between the patients and to keep an eye on potential infringements of the guidelines, the interaction in the community is working. To speak from the experience with the case www.krebsgemeinschaft.de, the role of the community manager turns the balance of the liveliness of a health care community.

4.2 Quality assurance

How can we differentiate our service from other information and interaction services which are not quality approved or of intransparent character? Boseley (2000) describes the Internet as a means that can fill any need but alongside with the potentials of the Internet and "the highly respectable sites are the well-meaning but just plain wrong - such as some of the proponents of vitamins as a cure for cancer […]". On the Internet anybody can publish information and recommendations. For the medical layperson it is oftentimes difficult to differentiate between scientific approved and 'bogus' therapies.

In order to overcome this problem an organisation called the Health Information System Action Forum ("afgis", see www.afgis.de), where krebsgemeinschaft.de is a member, started to work on the design of transparency criteria that should assure the quality of health information in new media and especially on the Internet (the criteria in the following printed in *italic*). Besides these criteria a sustainable process for quality assurance has been worked on. Web sites providers that are members commit themselves to fulfil the criteria catalogue and are allowed to carry the afgis logo.

On krebsgemeinschaft.de we implemented the criteria as follows: *Transparency about the providers* is given on the page 'about us' that can be reached from any page on the platform through a link. In addition the logo of krebsgemeinschaft.de is carried through all pages of our website so that it is always clear where the user is surfing at. *Goal, purpose and target group* of krebsgemeinschaft.de is indicated by the URL (which

can be translated as cancer community) and a statement on the entrance page and on 'about us'. All published content is stored in the content management system which holds the date of creation, time and author of each item which should ensure the *transparency of the authors and sources*. At the moment this data can only be seen by the administrator, content manager and community manager because all content is provided centrally from one of our partners, the Krebsinformationsdienst in the German Cancer Research Centre. Therefore there is only one author and source of information. Content that is generated by the external experts is treated differently (see the remarks in chapter 4.3 below). The *up-to-dateness* is shown by a stamp 'last updated on …' at the end of each page containing information. There are three links on each page: 'contact', 'feedback' and 'about us' where users can reach the project manager and the community manager or just ask questions and give us feedback – all possibilities to ensure that users have *an option for feedback*. There are several *quality assurance procedures*. There is the role of a community manager on the platform who is responsible for the moderation of the forums. Contributions of users that do not agree with the terms of use, published on the platform are commentated or in case of hardship deleted by him. Furthermore there is a privacy statement that explains what happens with the data accumulating during the registration process. *Transparency of advertising and editorial content* is inherently given because there is no advertising on the platform. Krebsgemeinschaft.de is funded by the German Ministry of Research and Education. This fact is communicated on the page 'about us' which also creates *transparency of cooperations and networks*. All the partners of the project are listed there in detail. Before the potential users can finish the registration form the *privacy statement* is pointed out.

4.3 Legal restrictions within the health care domain

As already mentioned before there is this contradiction between the need of the patient to get something like teleadvice (see also Eysenbach/Diepgen, 1999) and the restriction that in Germany a physician is not allowed to give advice or medical counselling to a patient without having seen him physically. Therefore it is difficult to implement services like an online consultation–hour where patients characterize their disturbances and get an advice or a prescription. But like our preliminary studies showed, there is a need for such a service on the German speaking Internet. Therefore we designed a related service called 'ask the expert'. Each month there is a special theme on the platform e.g. 'hormonal therapy' or 'diet and breast cancer'. The community manager recruits a specialist for the theme of the month who is answering questions about that topic. The questions and answers are displayed on a special board which can only be accessed by registered users. The guidelines say, that the experts should only provide generally accepted knowledge and always quote literature or studies about that topic. So far in theory.

   Reality shows that many experts do not really care about the fact that they are not allowed to consult patients virtually. Some of their answers just do not meet the standards we did put up for legally and socially accepted answers. Either they just wrote 'I suggest you to do this and that', 'In your case you should take this medicine...' or they used their medical lingo so that the questioner does not really understand the content. This is the point where the community manager comes into play and act as a mediator. One of his tasks is to double-check the answers of the experts for legal correctness and legibility. He also looks up references from literature, provides modules for standard answers, prefix (e.g. 'you should consult a doctor before you start any medication') and trailers which the experts add to their answers to ensure the quality.

5.   CONCLUSION

Beyond controversy, an online community serves as a means for patients to find information and to interact with other patients in a similar situation. Krebsgemeinschaft.de provides community users with features and the kind of information they usually do not get as easily and in such a convenient way anywhere else.

   But as we have shown in this article, there are several topics that need to be concerned before and during the development and maintenance of an online platform in the manner of krebsgemeinschaft.de. To ensure that the provided information and interaction possibilities meet the needs of the patients a continuous adaptation of requirements and an ongoing evaluation process are indispensable. In this article we accepted this challenge and introduced a development process and an evaluation framework for community platforms for cancer patients. The described models have been successfully used for the development of our platform.

Furthermore we gave an overview of the specialities within healthcare, like the specific legal restriction, the applied quality assurance model and the role concept. Of course these are results of a case study but we are sure that our research findings can give a valuable insight into the field community platforms within health care.

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