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KNOWLEDGE CREATION IN VIRTUAL COMMUNITIES OF PATIENTS: THE ROLE OF QUALITY ASSURANCE

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ABSTRACT

Virtual communities of patients provide health-related information and mutual support for their members. This paper presents a member centric knowledge creation process within virtual communities of patients. Our objective is to capture the importance of quality assurance of medical information available within virtual communities of patients. Furthermore, the role of the members as the main player in the quality assurance process is discussed and a knowledge creation process that involves the community and the operator is presented. This knowledge creation process fits the needs of these communities in terms of interaction, medical content and quality assurance aspects done by the members and the operator. The paper presents a full design cycle including an empirical study on the needs of virtual communities of patients, the design of a new e-service that fits these needs and the implementation of the knowledge creation process.

KEYWORDS

Virtual Communities of patients, e-health, knowledge management, knowledge creation, knowledge conversion

INTRODUCTION AND MOTIVATION

Virtual communities of patients (also mentioned as virtual communities in health care – VCHC) provide today mainly information and mutual support for their members. They offer information concerning diseases, treatments or new research results. Information shared among members includes experience reports on how the disease was contracted, how it affects the daily life and how to cope with it or even how to overcome it. In some VCHC, experiences with medical institutions, medics or treatments are being discussed (Dannecker and Lechner 2004). VCHC have a relatively long tradition as they were among the first virtual communities to emerge. Scientific and popular literature on virtual communities refers to various examples of VCHC as examples for innovative business models with great potential (Hagel III and Armstrong 1997; Rheingold 1994). Examples of successful virtual communities include: communities of cancer patients, women's communities of breast cancer patients, and communities of patients with chronic illnesses (e.g. (Josefsson 2004; Leimeister et al. 2004a)). We observe that little has changed for this kind of community over the past few years. The number of communities and the number of visitors and members have increased, but these communities are still concerned mainly with providing information and are a place for mutual support (Dannecker and Lechner 2004).

Patients also use other media apart from the VCHC to meet their need for information, social interaction and mutual support: Face to Face meetings, private conversation via phone, patient meetings organized by VCHC, physician patient seminars in which physicians and patients discuss selected topics related to the disease, or scientific conferences and congresses. Self-help groups that meet on a regular basis are another important way in the German health care system to organize the dissemination of health related information and mutual support of patients to patients. The topics that are covered by VCHC and self-help groups differ: treatments and medical information are typically an important topic in self-help groups while VCHC cover these topics in a very restricted way (Dannecker and Lechner 2004). E.g. some VCHC have developed a culture

to say that a certain treatment "helps me" but not that "it helps". Sometimes discussions about treatments are "forbidden". Although VCHC are important, they are not sufficient to meet all needs for information and social support of the patients today.

The exchange of experiences and knowledge within VCHC is crucial. Many VCHC share knowledge about diseases and possible treatments and a lot of information related to health care is available online. If knowledge conversion (KC) is understood as a process wherein an individual is affected by the experiences of another (Massey and Montoya-Weiss 2006). Thus, KC is done within the VCHC constantly.

This illustrates the need for methods and processes to support the knowledge creation within virtual communities. The objective of our research is to develop methods and processes to manage virtual communities of patients to increase the health related quality of life of patients. In our research we focus on communities of patients of chronic diseases. In this paper, we present as a theoretical contribution a model to support the design services an in particular services for quality assurance in virtual communities, the result of a first case study – the design of a rating service for rehabilitation centers and the theoretical foundations – the success factors of virtual communities of patients and a literature review.

The paper is structured as follows. The first part of the paper is a literature review of virtual communities and knowledge management. The second part presents the methodology including results of an empirical study, the design of a new e-service and the integration of this e-service within a community process. The paper concludes with a discussion on the results.

LITERATURE REVIEW

The objective of our research is to develop methods and processes for the management of virtual communities of patients and e-services to support these management processes. The literature review begins with the research area of virtual communities in general and the health care sector and virtual communities in the health care sector with their specific demand for services. As knowledge creation and management processes are the guiding models of the method, we briefly review knowledge management processes, communities of practice and services for quality management in knowledge creation.

VIRTUAL COMMUNITIES

Let us look at what defines the online world of virtual communities. The contributions of members distinguish virtual communities from other organizations or business models in the digital economy (Timmers 1998). Members contribute information and develop an atmosphere of trust which is prerequisite for collaboration or complex transactions (McKnight et al. 2002). Knowledge contribution and sharing is a complex and social process that involves different actors that have different needs and goals (McLure Wasko and Faraj 2005).

Rheingold describes how this social network emerges. He defines a virtual community as a 'social aggregation' that emerges in cyberspace ' when enough people carry on discussions long enough, with human feeling, to form "webs' of personal relationships' (Rheingold 1994). Virtual communities are characterized by rules of interaction, value system, mutual trust, common goals and interests (Figallo 1998; Preece 2000; Schubert 1999; Wellmann 2001; Whittaker and O`Day 1997).

Let us have a look at particular properties and the use of e-services. Based on Hamman, a virtual community can be characterized by: (1) a group of actors, (2) (social) interaction, (3) bonding between the actors and other members of the community and (4) the common place (Hamman 2003). Leimeister et al. have developed a ranking of technological, organizational and social success factors for virtual communities in general (Leimeister et al. 2004b). Particular to the field of virtual communities is the degree of differentiation. While contributions by members and social relations are keys for almost all communities, communities differentiate themselves in interaction, and the use of e-services according to their joint interest (Hummel and Lechner 2001). Moreover, the nature of the disease (Dannecker and Lechner 2004) and the need for new e-services (Dannecker and Lechner 2006a) leads to differentiation in e-service usage for VCHC.

HEALTH CARE AND VIRTUAL HEALTH COMMUNITIES

The health care sector is in a constant process of reorganization and offers new opportunities to new marketplaces and e-services (Kartseva and Tan 2005). People use the Internet to find health related information, manage their personal health record Online, get information about health care services and regulations that govern them (Goldschmidt 2005; Hulstijn and Tan 2005; Pratt et al. 2006). The integration of the information available via the Internet with information people received by physicians is an important factor to make complex personal decisions (Pratt et al. 2006). Dannecker and Lechner describe that there exists a demand on e-services that cover health related information that is supported by virtual communities of patients (Dannecker and Lechner 2006a; Dannecker and Lechner 2006b). Janke et al. postulate that patients in self-help

organizations are better informed on their disease than patients not attached to self-help organizations (Janke et al. 2005). Borgaonkar et al. show that providing 'disease-related information only' to patients worsens health-related quality of life (HRQOL) in inflammatory bowel disease (Borgaonkar et al. 2002). Interviews with operators of self help organizations confirm that providing information only and constantly reminding on the patient's illness (e.g. through mailing, brochures or newsletters) is counterproductive and frequently leads to the cancellation of the self-help organization membership. Kennedy et al. (Kennedy et al. 2003) showed '…patients given a patient-developed guidebook of self-management skills experienced significantly improved HRQOL'. This all together reminds that e-services that provide information only are not sufficient.

KNOWLEDGE MANAGEMENT

Knowledge management is a collective term for the facilitation of improvements to an organization's capabilities, efficiencies and competitive advantage through the better use of its individual and collective knowledge and information resources.

Davenport and Prusak (1998: p.5) contend that: "Knowledge is a fluid mix of framed experience, values, contextual information, and expert insight that provides a framework for evaluating and incorporating new experiences and information. It originates and is applied in the minds of "knowers". This means that knowledge is basically linked to the thoughts and experiences of human beings.

Knowledge is characterized as being tacit or explicit (Nonaka and Takeuchi 1995). The debate evolves around whether tacit knowledge can be made explicit, based on the working definition that tacit knowledge is not conscious to an individual and therefore could never be made explicit (Polanyi 1967). The definition of tacit knowledge has been adopted in knowledge management, enabling it to become explicit in some way (Cavusgil et al. 2003; Smith 2001). Tacit knowledge is in general regarded as referring to the internal information, knowledge and experiences as well as accumulated knowledge (know-how) that is linked to individuals. Explicit knowledge is codified information such as books, journals, documents, legislation, visual and audio recordings, digitized text, e-mail and the World Wide Web.

Knowledge management is also interested in turning tacit knowledge into explicit knowledge and vice versa in an constant growing and regenerating cycle, the so called "knowledge spiral" (Nonaka and Takeuchi 1995). In the context of VCHC it is important that the members of these communities share their knowledge and give other members the possibility to make decisions based on the knowledge of other members.

COMMUNITIES OF PRACTICE

Communities of Practice (CoP) are collaborative, interactive networks of individuals within a generally defined topic of knowledge. CoP facilitate knowledge sharing and organizational learning (Lave and Wenger 1991). According to Wenger and Snyder (Wenger and Snyder 2000), "people in communities of practice share their experiences and knowledge in free-flowing, creative ways that foster new approaches to problems". The adoption of these concepts is of importance to VCHC. The problems the members of VCHC face are manifold and the VCHC helps their members to understand them and to support the members in the best case with solutions. So, sharing the experiences of members to other members is an essential concept of VCHC. In the next chapter we present our methodology.

METHOD

We did a survey to find out about important factors and demand for e-services. A questionnaire was developed on the basis of a study of web communities , expert interviews with self-help group leaders, an empirical study of Leimeister (Leimeister et al. 2004b), and a literature review. The questionnaire consists of four parts. (1) Demographical aspects as age, gender, usage of the Internet etc., (2) aspects that cover the disease, (3) aspects handling the offline and online connection, and (4) questions to e-services and the social network. This fourth part consists of 34 questions to medical information and online content, quality assurance mechanisms done on contributions of members and the operator, role of the operator, technical issues, possibilities of interaction, and the emotional bonding of the members to the community.

Two versions of the questionnaire were created: one for the members and one for the operators of the VCHC. The operators provide the community platform and typically the contact data of operators are provided at the website of the community. Ten VCHC (we already had relations to these sites) were contacted to send their operators a first version of the questionnaire with the request to review the questionnaire.

We found VCHC in the German speaking context based on an Internet research done on Yahoo and Google. Cross linked sites in the context of VCHC were also taken into consideration. 250 VCHC in the German speaking context were identified.

VCHC with less than 50 members and communities with the most recent contribution older than one year were eliminated. This led to 117 VCHC from which 73 (63%) were chosen randomly and the ten VCHC to which the first version of the questionnaire was sent were added to the sample.

The questionnaire was sent to the operators of VCHC with the request to support the study, to provide a link to the questionnaire to their members, and to fill out the operator version of the questionnaire. The questionnaire was available in the Internet for three weeks in June 2005. After eliminating all empty entries and duplicate entries (same values and session id), 295 entries of members and 21 entries of operators formed the sample.

For interpretation and validation of quantitative results, qualitative interviews with operators and members as well as two presentations with the management team of two self-help organizations have been done.

DEMOGRAPHIC CHARACTERISTICS

People participating in this study are active in a total of 145 different VCHC. The 'Top Ten' of the VCHC according to the number study participants' account for about 50% of the participants (cf. Tab. 2).

Table 2. Top-Ten of the VCHC according to the number of study participants

|	VCHC	Number of participants	Ratio
1	rheuma-online.de (rheumatism)	50	11.74%
2	fibromyalgie-aktuell.de (pain patients)	35	8.22%
3	dccv.de (morbus crohn / colitis ulcerosa)	31	7.28%
4	croehnchen-klub.de (morbus crohn / colitis ulcerosa)	24	5.59%
5	sylvia.at (morbus crohn / colitis ulcerosa)	15	3.50%
6	diabetes-world.net (diabetes)	14	3.26%
7	prostatakrebse.de (prostate cancer)	14	3.26%
8	sd-krebs.de (thyroid cancer)	10	2.33%
9	leukaemie-betroffene.de (leukemia)	9	2.10%
10	kisp.de (prostate cancer)	9	2.10%

16 communities account for two study participants and 100 communities for one participant. More than 95% of the study participants are affected by a chronic disease. Most participants suffer from rheumatism (incl. fibromyalgie) (20%), followed by morbus crohn (17%), cancer (11%), diabetes (6%) and tinnitus (5%). Note that the majority of participants are affected by a chronic illness that allows an analysis on a homogeneous sample.

The research sample ($N_{members}$ = 295, $N_{operators}$ = 21) consists of 69% female and 31% male participants.

Particular for an online study are an average age of above 40 years and a very high percentage of women in the categories members and operators. This is also supported by quotes of participants within VCHC provided by the operators in follow up interviews. The participants contribute more than once a week in average. In average the members are affected by their illness for nearly 10 years, and their time of membership in average is two years and four months which is rather long, e.g. in comparison with the study of Leimeister et al. (Leimeister et al. 2005) where 25% of the membership period was less than 1 month (4.6% our study), 12.5% between 1-3 months (5.3%), 12.5% between 4-6 months (9.6%) and 50% longer than 6 months (80.5%). So the sample includes a lot of experienced community members and community members seem to stay relatively long within the VCHC.

INFLUENCE FACTORS WITHIN VCHC

The research model (cf. Fig 1) captures the factors that influence the bonding in virtual communities. (Dannecker and Lechner 2006a)
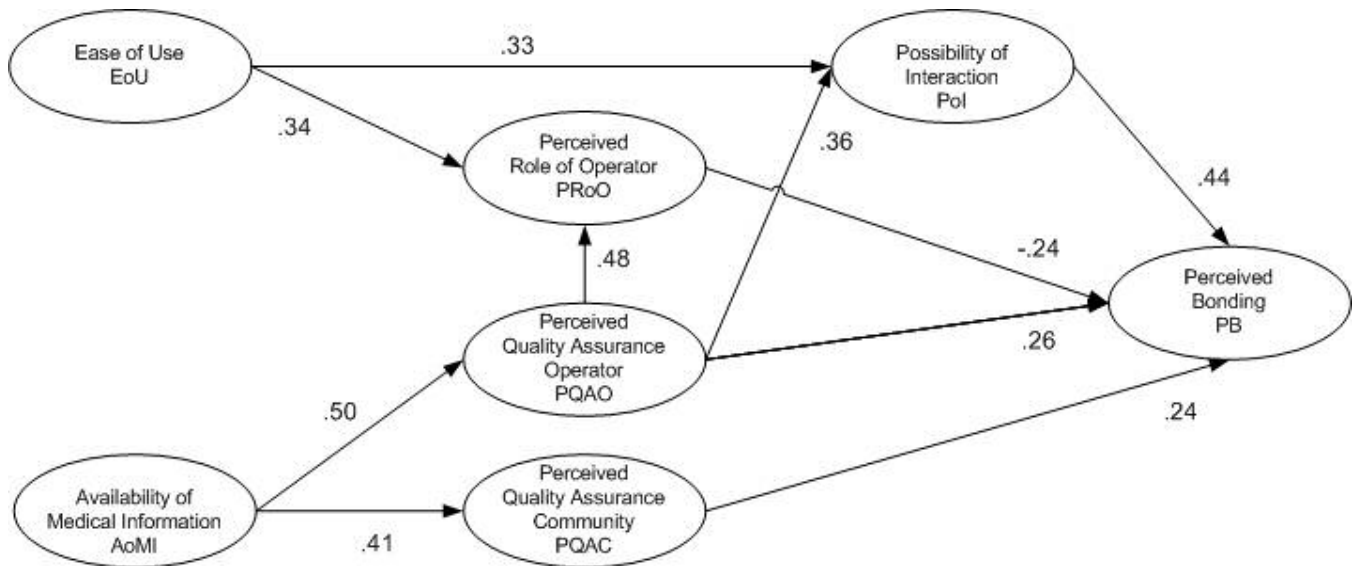
Figure 1. Structural equation model (members of VCHC) following (Dannecker and Lechner 2006a)

The structural equation model was estimated by AMOS 5 (Byrne 2001) using a maximum likelihood estimation. The values of the model are within an acceptable range (RMSEA=.033). All standardized regression coefficients are significant at p<.001 (beside PQAO->PB p=.009 and PRoO->PB p=.002). In Fig. 1 only the latent variables are shown.

Let us explain this model and relate it to examples and theory. All latent variables lead to the latent endogenous variable "Perceived Bonding" (PB). "Perceived Bonding", i.e., the social relations among community members and between community members and the community and the community site distinguish the business model community (Hagel III and Armstrong 1997; Hummel and Lechner 2002; Schubert 1999). Interaction strengthens these social relations (Jones and Rafaeli 2000; Kollock and Smith 1999) and this is reflected by the model as the direct effect of "possibility of Interaction" (PoI) to PB is the strongest.

The "Availability of Medical Information" (AoMI) on the site influences PB only indirectly via "Perceived Quality Assurance of Medical Information" by the community (PQAC) and by the operator (PQAO). PQAC and PQAO reflect contributions to the community with aspects like "Discussions about alternative methods of treatments" or "statement about clinical institutions". Note that this indirect effect (.25) is as strong as the one of PQAO, PQAC and "Perceived Role of the Operator" (PRoO) inversely. Let us compare this with reality and literature. The typical community site architecture features an "information only" area and little means for interaction with little relation between these two parts. In practice, the two parts do not benefit from each other and could very well exist on different sites.

It is the interconnection between community and information, the process of establishing a common understanding of the field of interest, a common body of knowledge, trust and common values that distinguishes a community (Hagel III and Armstrong 1997; Hummel and Lechner 2002; Preece 2000).

Quality assurance methods by the community are one way to establish this common understanding, these values and norms centered around a collection of medical content, e.g., research reports, scientific articles and popular information. Comments, recommendations, ratings, ratings of ratings or reviews are means to implement this quality assurance in communities. VCHC typically have a common opinion about, e.g., preferred treatments and alternative medicine. The community is a kind of filter which helps to select the pieces of information which fit the common opinion or to translate pieces of information from scientific articles so that it can be understood by the community (Dannecker and Lechner 2004).

Also, the role of the operator in quality assurance (PQAO) is important and strengthens the bonding. Again, this is reflected by literature as the community and the operator need a common understanding of the field of interest. In practice, providing relevant information is the role of a community operator. The role of operators who typically control a community in terms of member satisfaction, member interaction, and growth (latent variable PRoO) is not beneficial for the community. Several authors describe that communities do not want controlling and operators that invest heavily in community controlling (instead of investing in content) are assumed to have a more commercial interest in the community (Hagel III and Armstrong 1997).

Interaction, e.g., online and offline events (PoI) strengthen bonding and ease of use (availability, reaction time and usability of the web site of the community) are prerequisite for good interaction. Again this is mirrored by the path EoU->PoI->PB in Fig.1. An operator that promotes interaction, e.g., through special events, can benefit from good medical content (AoMI) and strengthen the bonding of the community (AoMI->PQAO->PoI->PB in Fig. 1).

Two major aspects are the result of the empirical work. First, Interaction issues (PoI) do have the greatest influence towards the perceived bonding (PB) of VCHC members. Part of the interaction issues is setting up meetings in real life and push of interaction between members. Second, quality assurance issues (PQAO, PQAC) are important to members. Parts of these quality assurance issues are statements of members about physicians, clinical institutions, alternative methods of treatments

etc. In the offline world these topics are part of discussion in self-help groups (Borgetto 2004). To discuss and to exchange information concerning these topics is important to participants of self-help groups. Dannecker and Lechner identify three dimensions to analyze the needs (Dannecker and Lechner 2006a): age, time people are affected by a disease, and the time of membership in VCHC. Typically statements of members about medical aspects are done in an unstructured way within the forum or a chat. This can lead to a bad atmosphere within the VCHC an there fore operators often forbid discussions about medical aspects in terms of is it good or not(Dannecker and Lechner 2004). To solve the problem between the need of the members to discuss medical aspects and the unstructured discussions about medical aspects we have designed and implemented an e-service that allows members to contribute their knowledge about relevant medical aspects in a structured way.

DESIGN AND IMPLEMENTATION OF AN E-SERVICE FOR USER BASED RATINGS

Quality assurance for medical information was identified to be important for VCHC. An e-service for quality assurance was developed together with the „Deutsche Morbus Crohn / Colitis ulcerosa Vereinigung DCCV e.V. (www.dccv.de, DCCV)" a patient organization that takes care of patients with "Inflammatory Bowel Disease". The service is for the members of the DCCV available since summer 2006. The service was designed to support the factors (cf. Research model, Fig 1). This e-service enables a VCHC to design, set up and run a quality assurance process by itself. The main components of the e-service are: (1) A back-end to administrate and setup a rating process, (2) a front-end for users to rate, (3) a generic database and (4) an evaluation mechanism to compute a rating.

The e-service is implemented as an extension to Typo3 (www.typo3.com). The extension consists of a module to configure the questionnaire from an administrative perspective and a plugin that generically displays the questionnaire and the results with in the Typo3-pages.

The e-services supports for a rating (a rating is calculated by a set of single ratings of different users) the following possibilities:

- A user rating can be rated by another user in terms of "whether the rating was helpful or not"
- A rating is displayed after a specific number of user ratings. This should strengthen the rating – single, perhaps a statement that tends to a different direction, ratings will not be displayed and be qualified by a greater number of user ratings.
- A rating is displayed only if a certain threshold is reached. This filters bad and possible unfair ratings. Only positive ratings will be displayed due to legal issues.
- Only registered users can rate the content. The username can be economized to support anonymity – if necessary – for users of a VCHC.
- Based on the age of the contributions the ratings can be filtered. This allows making tendencies visible regarding the development of a rating.

The template supports text based questions; Yes/No questions and scale based questions.

The designer of a questionnaire decides whether questions are optional and the weight of the question. For some questions the users can set a weight for questions as well. The framework contains also a standard evaluation package to compute the rating of each item.

The first application domain for which the service is used by the DCCV is the rating of rehabilitation centers. The objective in the design is to maximize participation of the community such that the knowledge conversion supports bonding and interaction as well. Let us present our research framework and the design of the rating service in the next section.

KNOWLEDGE CREATION PROCESS

The rating of medical relevant information within VCHC is part of a knowledge creation process within VCHC. We distinguish five phases in this process. The process is depicted in Fig. 2. Each phase has impacts (outcomes) to the components of the research model (cf. Fig 1).
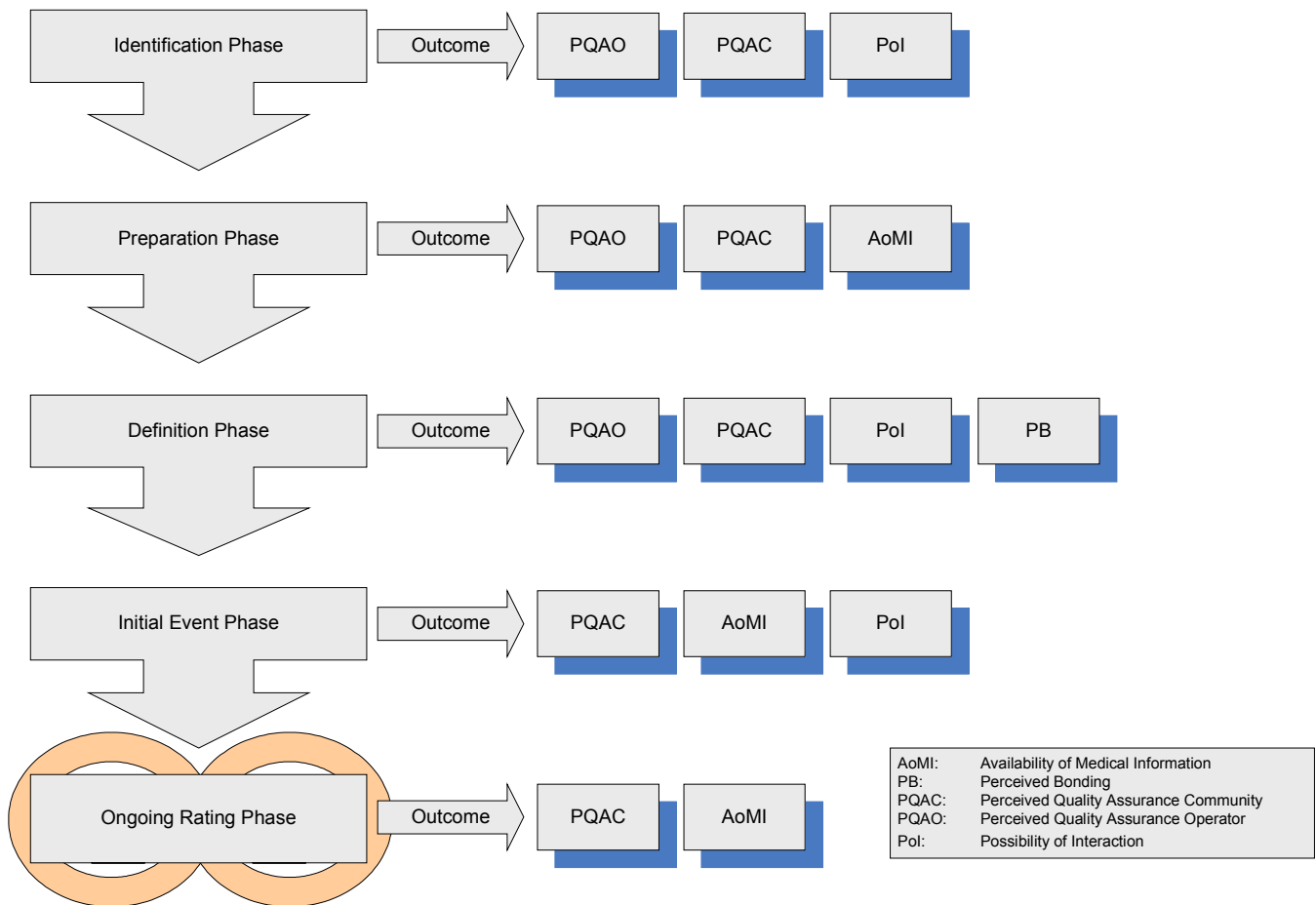
Figure 2. The five phases of the knowledge creation process

Let us explain the five phases and the options an operator has to design the phases. We are interested which components of the research model are being supported in the various phased of the knowledge creation process. Our hypothesis is that maximization of participation benefits the bonding and therefore the VCHC.

1. *Identification Phase*: The identification of an interesting and relevant topic can be done according to three different scenarios. (I) Semi automatic by "observing" the user clicks within the site, forums and chats. An editor (operator as well as a member) may approve if the topic is indeed relevant. Reflecting the research model (cf. Fig. 1) this supports either PQAO or PQAC. (II) By a survey as part of an event (PoI) of the VCHC to determine topics that are important to the members. This supports PQAC. (III) Operators or users just provide a topic.

2. *Preparation Phase*: After identifying a relevant topic, it is necessary to prepare medical information related to the chosen topic. This information may be clinical studies, scientific papers, field reports, expert interviews, and news, threads within the forum or chat and the information contributed by participants. This can be done either by the operator - this supports PQAO - or by the members who can be involved within this process this supports PQAC.

3. *Definition Phase*: The definition of the rating criteria for a specific part of information that is relevant can be designed to be a community process. In a first step, possible criteria are collected by an online discussion event. VCHC can initiate so called "expert chats" in which the community is able to talk online with experts to a specific topic. So the same functionality and process can be used to discuss rating criteria for medical information, this supports both PoI and PQAC. Crucial is that the common development of these criteria fosters a common understanding of the community on the meaning of the criteria. This supports the PB of a community. If the operator gets involved within the definition of the rating criteria PQAO is supported as well.

4. *Initial Event Phase*: An initial rating event promotes the service within the community as a new feature, creates attention and helps to reach a critical mass of ratings . The main objective of such an event is to involve the community in a first step to contribute and rate a specific type of content that is part of the topic the VCHC has chosen. This supports PQAC and PoI and as the result of such an event is again new user generated medical relevant information it also supports AoMI.

5. *Ongoing Rating Phase*: The last phase constantly generates new medical relevant information by the members, which supports both PQAC and AoMI.

This process illustrates that a quality assurance process is an important factor in the knowledge creation process and vital to a VCHC. The design and implementation show the feasibility of rating medical information within VCHC which is hardly

attempted by big VCHC. This theoretical analysis of the process shows the impact that a well designed process eventually has on VCHC.

DISCUSSION

Sharing and creating knowledge is an important issue within VCHC. The better the integration of the community within the VCHC is, the tighter the community will be. Operators have to think about the way they administrate their community. From a members' perspective involving the members into the community organization and especially in terms of contribute relevant quality aspects is important. Creating knowledge in terms of quality based statements to medical issues done by the community for the community will is in the main focus of VCHC. Embedding this issue within a process that also supports interaction should be considered by the operators as important, because it reflects the needs of the members of VCHC. We have shown how to integrate these issues within one knowledge creation process. We expect that this process improves the VCHC and helps them to contribute in a more structured way.

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