

On the Demand for E-Services by Health Communities

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Abstract: Virtual communities of patients provide health-related information and mutual support for members. This paper presents an analysis of the demand of virtual communities of patients for novel electronic services. Results include the success factors of virtual communities of patients, the demand for electronic services for new and experienced community members and the demand for electronic services for short-term affected and long-term affected patients.

1 Introduction

Virtual communities of patients (also referred to as Virtual Communities in Health Care – VCHC) provide information and mutual support for their members. VCHC provide information concerning diseases, treatments or new research results in the area of interest. Information shared among members includes experience reports on how the disease was diagnosed, how it affects the daily life and how to cope with it. Experiences with medical institutions or treatments are sometimes topic in VCHC.

Our research on success factors and e-services for VCHC is motivated twofold. First, we think that strong VCHC benefit patients, as patients look for reliable information, need mutual support and orientation. Second, we think that novel e-services are able to strengthen VCHC by attracting more members, by motivating them to contribute more and by collecting more and different kinds of information.

In our research of VCHC we established a model to capture the success factors of VCHC and the mutual dependencies of these success factors [DL06c; DL06a]. In this paper, we present the results of an analysis of the success factors of subgroups of users of those communities. The objective of community management is to attract members of the target group and convert them to long-time and active users. We compare new and long-term members as well as newly affected and long-term affected members. Our goal is to identify success factors, i.e. design issues for e-services and communication management, and derive adequate e-services. Our indicator for success is active contribution by members. Our guiding hypothesis is that communities should attract members early and keep them for a long time as active members. A large number of active members with diverse profile benefit the community to perform better in providing information and mutual support.

The paper is organized as follows. We discuss the state of the art (Sect. 2), present the research approach (Sect. 3, 4), success factors (Sect. 5) and discuss then success factors for subgroups (Sect. 6, 7 and 8). A discussion concludes the paper (Sect. 9).

2 State of the art

The health care is in a process of reorganization and people use the internet to find health related information, manage their personal health record via the internet, get information about health care services and regulations that govern them [Go05; HT05; PUC06]. The integration of the information available via the internet with information people received by physicians is an important factor in health-related decisions [PUC06].

Self-help organizations and self-help groups are the “traditional”, off-line form for people that are affected by a disease to exchange experiences. Self-help organizations typically inform members about all aspects of a disease and they act as representative (patient unions). Janke et al. postulate that patients in self-help organizations are better informed on their disease than patients not attached to self-help organizations [JKG05]. Borgaonkar et al. show that providing disease-related information only to patients worsens health-related quality of life (HRQOL) in inflammatory bowel disease [BTD02]. Interviews with operators of self help organizations confirmed that providing information only and constantly reminding on the patient’s illness (e.g. through mailing, brochures or newsletters) is counterproductive as it leads to a decrease of HRQOL and, frequently, to the cancellation of the self-help organization membership. Kennedy et al. [KRN03] emphasizes “...patients given a patient-developed guidebook of self-management skills experienced significantly improved HRQOL”. This indicates that e-services that provide information only are not sufficient to benefit patients. A study to the effectiveness of Australian Medical Portals (medical information only) shows that users find them useful[MF06]. This indicates demand for medical information.

Participants in self-help groups meet on a regular basis mainly to exchange information related to a disease. Self-help groups have two main goals: mutual support and exchange of information [Bo04]. Participants benefit from experiencing that they are not the only one affected by a disease or the only ones disease related problems in the daily life. Topics discussed in self-help groups include medics, clinical institutions, rehabilitation centres, treatments, medicaments, research and participation in clinical studies. Note that this variety of topics is not found in online self-help groups [DL04].

Online communities or at least forums are part of online-offerings of self-help groups. An interview partner (community manager) describes the typical situation and that little has changed in the past years – as the forum has the size of approximately 100 regular, but mostly not long time visitors. Similar “newbie” questions are being asked over and over again, with the same (eventually dangerous) theories about origin of the disease and possible cures being discussed in a not so profound way, with newly diagnosed people asking one or two urgent questions and leaving again. Only relatively few people stay and profound discussions take place only partly online in the forum. This self-help organization is proud of the collection of relevant medical information it provides.

3 Research method

The objective of our research is to find out what services virtual communities of patients help to perform better in providing information and mutual support.

A questionnaire was developed on the basis of a study of web communities [DL04], interview with self-help groups leaders, an empirical study of Leimeister et al. [Le04b], and a literature review. Two versions of the questionnaire were created: one for the members and one for the operators of the VCHC, i.e. for the persons that maintain a community and that provide the platform. Note that operators are typically also members of VCHC. Ten VCHC (we already with their operators) were contacted to send the community operators a first version of the questionnaire for a review. We identified 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 discarded. This led to 117 VCHC from which 73 (63%) were chosen randomly. The ten VCHC to which the first version of the questionnaire was sent were added to the sample. The questionnaire was sent to the VCHC operators with the request to support the study, to provide a link to the questionnaire to VCHC members, and to fill out the operator questionnaire. The questionnaire was available for three weeks in June 2005. All empty and duplicate entries were eliminated and 295 entries by members and 21 entries by operators form the sample. For interpretation and validation of quantitative results, interviews with operators and members as well as presentations with the management of two self-help organizations have been done.

The information that we requested from study participants included the usual demographic information with age, gender, time online, number of VCHC the study participant is a member of, and for how long she is affected by the disease.

	VCHC	No 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%

Table 1: Top 5 of the VCHC according to the number of study participants

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, the “Top 5” for 38%. 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 disease which allows an analysis on an homogenous sample.

The research sample (Nmembers = 295, Noperators = 21) consists of 69% female and 31% male participants.

Type	Selected Questions/ Statements
Social/Altruistic issues (S)	That people understand you with your problems Assistance for new members by experienced members The feeling to be in a place at home
Technical issues (T)	Stability of the website Fast reaction time of the website
Medical Content (MC)	Offering up-to-date information and information about relevant clinical trials Push of research within the field of your disease
Medical Quality Assurance (MQA)	Contributions of members/operators for members e.g. Active quality assurance of the content of the community done by members Statements of the community about medics Possibility of discussions about alternative methods of treatment Moderation of member contributions by the operator

Table 2: Types of success factors / Topics and Questions

Particular for an online study are an average age of above 40 years and a high percentage of women in the categories members and operators. The participants contribute more than once a week in average. In average, the members are affected by their illness for nearly 10 years with a VCHC membership of twenty-eight months. Note that the high percentage of woman is typical for health related online communities in general. Note that the illnesses of most patients inflict both men and woman and that this does not explain the high percentage of women in this study. The high average age of the study participants coincides with occurrence of chronic illnesses typically later in life. Let us give a brief impression of the questions in the study as summarized in Tab. 2.. We had questions concerning the social network of a community following the literature on virtual communities as discussed e.g. in [DL06c; DL06a], the technical aspects of services and infrastructure, the attitude towards medical content in communities and the support of medical research, the attitude towards quality management in the health care sector done by the community.

5 Success Factors

Let us analyze the success factors (i.e. what is relevant to members) of VCHC. The 7 most important success factors are ordered according to the member perspective in Fig. 1. The figure contains an abbreviated version of the original question and the arithmetic mean of the answers. The sample was tested due to normal distribution using an exact “Kolmogorov-Smirnov-Test”. All results are significant with $p<.001$.

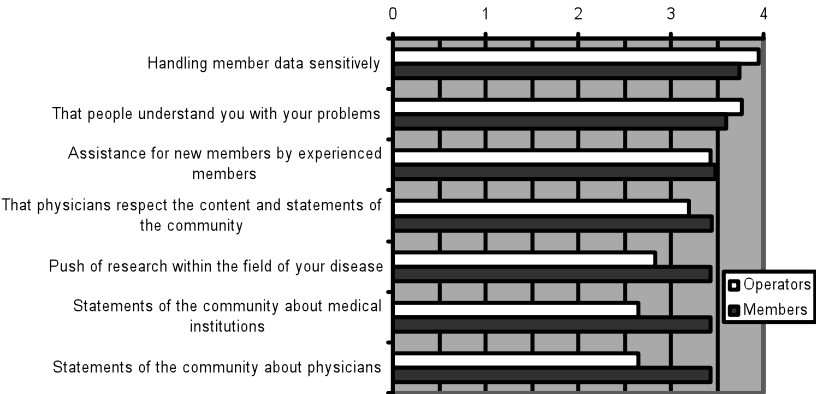


Fig. 1. Top 7 success factors ordered by the member views (highly agree 1 – highly disagree 5)

Handling member data is the most important factor for the members and it is considered even more important by operators. The feeling of being understood with problems within the VCHC is next, followed by the assistance of new members by experienced members. Note that success factors concerning medical issues and medical quality issues are important and of special interest to the community. These factors are statements of the community about medical institutions and physicians and support of medical research.

The difference between operators and members occurs in aspects concerning the medical information a community contributes (that physicians respect the content available in communities, statements of the community about medical institutions and physicians and offering up-to-date information about medical trials). This is reflected by the current situation as VCHC hardly provide e-services for members to contribute experiences with physicians or treatments. This difference is explained in interviews with operators: Operators are concerned whether such kinds of contributions would be feasible or whether members would appreciate such kind of e-services.

6 Target Group Specific Demand

We assume that VCHC can be effective in communicating authentic and important disease related information and providing mutual support. Therefore it is desirable to reach patients that just have been diagnosed and are affected for a short time by the disease (short-term affected) as well as patients that have been affected for a long time (long-term affected). Our guiding hypothesis is that it desirable to attract visitors and to keep members for a long time. We look into the differences in demand for e-services between community newbies and experienced community members and between newly affected and long-term affected patients to find out which e-services attract new members or newly diagnosed patients and which services are relevant for experienced members or long term afflicted patients. First, we analyze the relation between the time of membership in VCHC and the time the members are affected by their disease.

		Affected since (years)							Total
		< 1y	< 2y	< 3y	< 5y	< 10y	< 20y	>= 20y	
Member since (months)	< 3m	4			1	3	4	3	15
	< 6m	7	2	3	3	5	7	1	28
	< 9m	4	3	1		2	2		12
	< 12m	7	8	3	6	8	5	2	39
	< 18m	1	6	5		1	3	2	18
	< 24m		6	8	9	9	12	8	52
	< 36m			14	7	13	12	5	51
	>= 36m			2	12	20	11	11	56
Total		23	25	36	38	61	56	32	277

Table 3.Time of membership vs. time affected by disease

Note that our study indicates no significant correlation between the time the people are affected by a disease and the time the people are member of a community (bivariate correlation based on Pearson .043, significant at p=.480). Tab. 3 shows the distribution of the members regarding the time people are affected by their disease and the time of membership.

VCHC are a rather new phenomenon compared to the time people are possibly affected by a chronic disease. We distinguish between the timeframe regarding the time people are affected by their disease (less than 1 year...more than 20 years) and the time people are a member of the VCHC (less than 3 months...more than 36 months). We observe (Tab. 3) that 9 study participants were longer affected that 5 years but are member of a VCHC for less than three months. 28 study participants are less than 6 months member of a VCHC and 21 of those 28 members are affected for more than 5 years. In the category “members longer than 3 years” (36 months) almost all study participants are affected by the disease much longer. Note, that this lack of relation between length of community membership and time people are affected is an indicator that VCHC do not attract newly diagnosed patients very well. Let us discuss whether communities are able to bind members and transform visitors to members. A lot of study participants are member for either a relatively short time or for a rather long time (longer than 24 months). The increase of respondents from members <3 months to members <6 months is an indicator that new members stay for some time. The results for study participants with memberships longer than 6 months and less than 24 months are inconclusive. This is an indicator that new members stay for a while, but that some members leave. Long-term members seem to be quite loyal. This indicates that VCHC bind active members.

7 New vs. experienced members

We assume that the interests and needs of members that are new to a community typically differ from the ones of long-time members. Keeping new members, activating passive, non contributing members or keeping active members active are considered important goals in community management [HA97; Pr00].

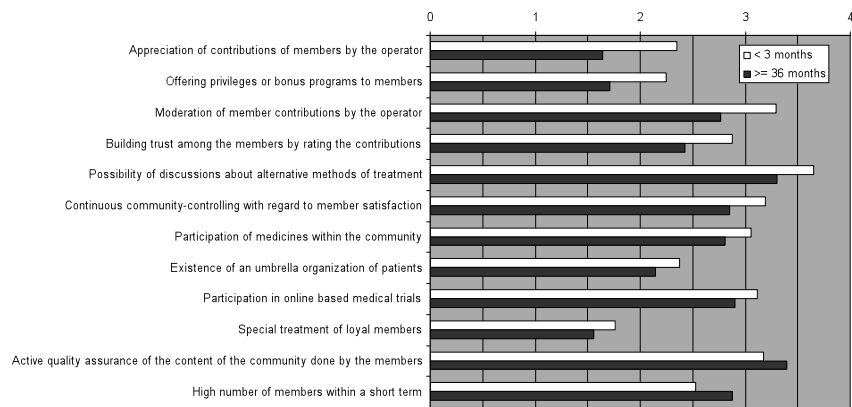


Fig. 2. Main differences in importance to success factors by the view of newbies and experienced members (sorted by difference >= .2) (highly disagree 0 – highly agree 4)

To determine whether there are pair wise associations for the sets of normally distributed variables a “Bivariate Correlations” examination based on “Pearson“ was executed. All correlations w.r.t. the time people are member of a VCHC and the success factors are significant at $p < .001$. In Fig. 2, the main difference ($\geq .2$) in success factors between the view of newbies (member less than 3 months) and experienced members (member more than 36 months) is depicted.

The role of an operator, moderator and medical experts and an umbrella organization is more important for newbies than for experienced members according to the results presented in Fig. 2. Experienced members seem to have more trust in community and most likely are more aware of the self-organization processes and the power of the community. Newbies rely more on formal qualifications (physicians), distinctive roles (operator, moderator) and formal processes (medical trials). Newbies are interested in discussions of alternative treatments and in rankings of contributions. Interviews confirmed that information about alternative treatments attracts visitors.

Experienced members are more interested in other community members (meeting community members offline, number of community members), usability of the website (intuitive user guidance) and in quality assurance done by community members (Active quality assurance of the content of the community done by the members).

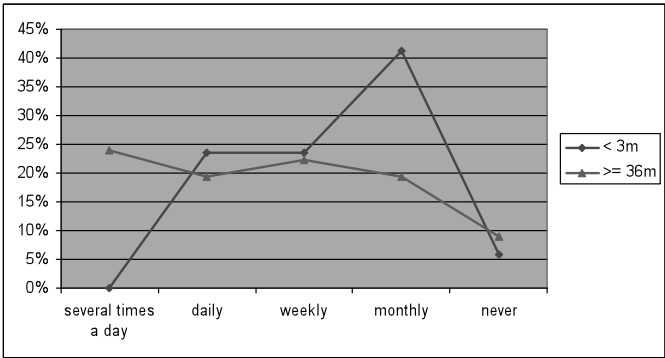


Fig. 3. Distribution of postings. Newbies (< 3m) vs. Experienced members (> 36m)

They seem to be more interested in community and seem to have more confidence in what the community can contribute. Note that the bonding to the VCHC is more important to the experienced members than it is to newbies (e.g. “Does the community play a central role”). A formal organization and the presence of medics is important for newbies as this signals orientation and professionalism. For experienced members the interaction is important.

Let us have a look on the contributions of newbies and experienced members. Experienced members contribute more often than newbies. Fig. 3 depicts the difference from posting “several times a day” (newbies 0%, experienced members 24%) up to posting “monthly” (newbie 42%, experienced members 19%).

Newbies (< 3 months)			Experienced members (>= 36 months)		
Success factor	Ø	Type	Success factor	Ø	Type
Handling member data sensitively	3,82	S	Handling member data sensitively	3,77	S
That people understand you with your problems	3,71	S	That people understand you with your problems	3,61	S
Possibility of discussions about alternative treatment	3,65	MQA	Stability of the website	3,49	T
Push of research within the field of your disease	3,47	MC	Assistance for new members by experienced members	3,42	S
Assistance for new members by experienced members	3,41	S	Active quality assurance of the content done by the members	3,39	MQA
Statements of the community about medics	3,41	MQA	Establishing codes of behavior(netiquette/guidelines)	3,33	S
Fast reaction time of the website	3,35	T	Fast reaction time of the website	3,31	T
Offering up-to-date and relevant clinical trials	3,29	MC	Sustaining neutrality when presenting and selecting offers	3,30	S
Statements of the community about medical institutions	3,29	MQA	Statements of the community about medical institutions	3,29	MQA
Moderation of member contributions by the operator	3,29	MQA	The feeling to be in a place at home	3,26	S

Table 4. Top Ten of important factors by newbie and experienced member view

Interesting is that distribution of contributions of experienced members (except for “never”) is nearly equal at about 20%. There are long-term and active members as well as long-term and passive members.

Social aspects are important to experienced members (Tab. 4). This coincides with the higher participation of experienced members within self-help groups and that they know more people of their VCHC in real life [DL06c; DL06a].

For newbies as well as experienced members “Handling member data sensitively” and “That people understand them” are the most important factors.

Type	Newbies (< 3 months)	Experienced members (>= 36 months)
Altruistic/ Social issues (S)	3	6
Technical issues (T)	1	2
Medical Content (MC)	2	0
Medical quality assurance (MQA)	4	2

Table 5. Summary - Top Ten important factors of newbie and experienced members

The differences in the needs of newbies and experienced members are summarized in Tab. 5. For newbies, social issues as well as medical issues (medical content and medical quality assurance) are in their focus. For experienced members the altruistic and social aspects (S) are dominant. For both, the medical content (MC) within VCHC seems not to be important. This coincides with the theory on virtual communities – contribution of members and social aspects are key.

8 Newly affected vs. long-term affected members

As in the previous section – the differences concerning the attitude of newly affected and long-term affected patients towards success factors is analyzed first.

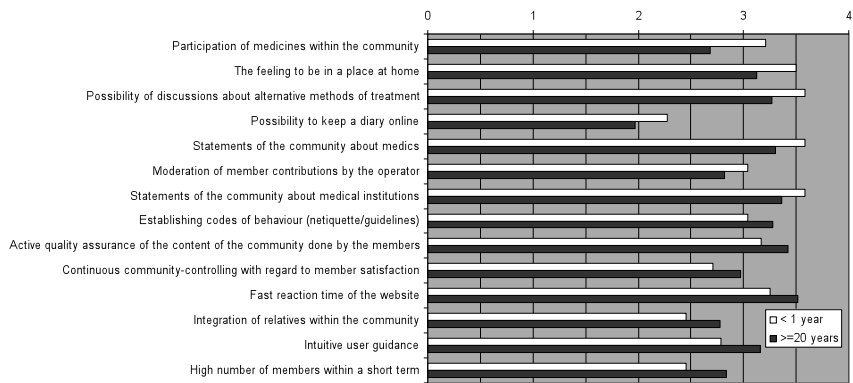


Fig. 4. Main differences in importance to success factors by the view of newly affected vs. Long-term affected members (sorted by difference $\geq .2$) (highly agree 4 – highly disagree 0)

Fig. 4 depicts the main differences ($\geq .2$) between the view of newly affected and long-term affected patients. To determine whether there are pair wise associations for the sets of normally distributed variables a “Bivariate Correlations” examination based on “Pearson” was executed. All correlations w.r.t. the time people are affected by their disease and the success factors are significant at $p < .001$.

Let us first discuss the factors that are more important to the people affected less than a year than to people affected for a very long time. We see that information about medical issues by the community, about treatments and medical institutions, and medics is important. Again, as in the previous section we see the importance of medics, and of formal roles within the VCHC (moderator, neutrality of the community). The feeling at home in the virtual community is also important for newly affected members. For members that are affected for more than 20 years, community aspects, e.g. netiquette, high number of members, the controlling of a community, the contributions of members as well as technical issues about the website (fast reaction time, usability) are more important.

The next step is an analysis of the activity of the two groups. In contrary to the time of membership the time members are affected by their disease does have only little impact to the number of contributions. Fig. 5 illustrates that there is just a small shift from “several times a day” (short-term affected 0%, long-term affected 12%) to daily (short-term affected 33%, long-term affected 21%).

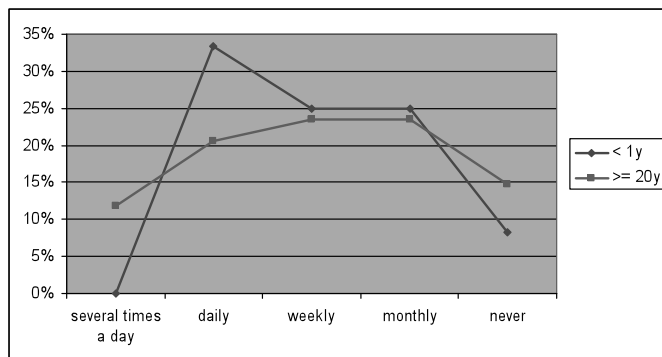


Fig. 5. Distribution of postings. Short-Term (< 1y) vs. Long-term affected (>= 20y)

Note that the ratio contribution/time spent in VCHC of short-term affected members is half of the ratio of long-term affected patients. Thus, short-term affected members spent more time just consuming content.

Short-term affected (< 1 year)			Long-term affected (>= 20 years)		
Success factor	Ø	Type	Success factor	Ø	Type
Handling member data sensitively	3,83	T	Handling member data sensitively	3,91	T
That people understand you with your problems	3,63	S	Stability of the Website	3,61	S
Statements of the community about medics	3,58	MQA	Push of research within the field of your disease	3,56	MC
Possibility of discussions about alternative methods of treatment	3,58	MQA	That people understand you with your problems	3,55	S
Statements of the community about medical institutions	3,58	MQA	Assistance for new members by experienced members	3,52	S
Assistance for new members by experienced members	3,58	S	Fast reaction time of the website	3,52	T
Push of research within the field of your disease	3,50	MC	Statements of the community about medical institutions	3,36	MQA
Stability of the website	3,37	T	Offering up-to-date and relevant clinical trials	3,34	MC
Offering up-to-date and relevant clinical trials	3,33	MC	Encouraging interaction between members	3,21	S
Participation of medics within the community	3,21	MQA	Arranging regular events	3,08	S

Table 6. Top Ten of by short-term and long-term affected member view

For short-term as well as long-term affected members “Handling member data sensitively” and “That people understand them” are the most important factors. Note that 7 out of the 10 most important success factors are in both top ten lists (see Tab. 6). This is an indicator that the time how long members are being affected does not change that much in the needs for e-services.

Type	Short-term Affected (< 1 year)	Long-term Affected (>= 24 years)
Altruistic/ Social issues (S)	2	5
Technical issues (T)	2	2
Medical Content (MC)	2	2
Medical quality assurance (MQA)	4	1

Table 7. Summary - Top Ten factors by short-term and long-term affected member view

Tab. 7 summarizes that for short-term affected members quality assurance issues are in their focus, social, technical and content aspects are of minor interest. For long-term affected members medical and social aspects are dominant. The (pure) content does play only a minor role. Interaction and social relations are the key to attract and keep members that are affected for a long time while medical information and in particular the quality assurance done by community members is the key to attract short-term affected members (that most likely have been diagnosed recently and are looking for neutral and authentic information about disease, medical institutions and treatments).

9 Conclusions

The objective of our research is to obtain insights in what is important to virtual health communities and to various subgroups within virtual health communities. The results include the most important aspects in design and services – the success factors for virtual communities. The analysis of the relation between time of membership and time how long people are affected illustrates that today health communities do not attract the newly diagnosed very well and that they do not bind and keep members very well. The study on the differences between success factors of new members and experienced members show the differences in the needs of those two subgroups: for the newly diagnosed, it is medical content and social interaction and for the long term members, social interaction and altruistic motives dominate their perception of what is important to virtual communities. When we compare this to the differences in success factors that originate in the time people are affected by the disease we observe that a clear tendency in that altruistic and social issues are more important to long-term members while medical quality assurance is more in the focus of new members. We conclude that virtual communities indeed need a more differentiated and richer set of services than what currently is part of a community platform as precondition for eventually empowering virtual communities of patients.

This analysis of the demand for e-services has been done for a very special kind of community. Some results of the study coincide with the literature in the field of services or platforms for virtual communities. The study shows differences in demand for e-services for various subgroups and this illustrates the necessity for profound research and requirement specifications for communities in general.

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