

Please quote as: Hartmann, M.; Bretschneider, U. & Leimeister, J. M. (2012): Making patients to innovators - The case of the Ideenschmiede . In: R&D Management Conference 2012, Grenoble, France.

Making patients to innovators

– The case of the Ideenschmiede

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Submission number. 155

Abstract

Online communities are a very interactive places where patients communicate with each other about diseases, therapies, how to deal with diseases and about personal experiences made. They also develop and share innovative ideas, which shall make their all day life easier. But this happens mostly in an unsystematic and uncontrolled manor. To support this ideation process we developed a module called “Ideenschmiede”, which extends existing online patient communities in order to support the collaborative and systematic idea development. For doing so we looked out for an existing online community within the healthcare sector, in which patients already develop ideas. Against this backdrop, this research in progress article addresses the following question: “How can existing online communities for patients be expanded in order to enable a structured ideas development by patients?”.

Keywords: Open Innovation, Healthcare, Online Communities

1. Introduction

The internet and especially online communities are important for patients and relatives of patients to gather information about diseases, potential therapies or drugs (Bohnet-Joschko & Bretschneider, 2008; Hartmann et al., 2011; Leimeister, 2005). Online communities enable members to interact with each other and they allow their members to develop a sense of

belonging to the community. (Blanchard, 2004) defines online communities as “Groups of people who interact primarily through computer-mediated communication and who identify with and have developed feelings of belonging and attachment to each other.” It follows that online communities can be a central location for patients. In online communities members can interact anonymously and independently over time and space about how they deal personally with a disease and how a disease can be mentally processed. The participating in an online community can also help to find solace and social assistance (Leimeister & Krcmar, 2006).

Online communities are also increasingly used by patients in order to exchange and discuss ideas, which facilitate the daily life of patients. According to (Lüthje, 2004), who pointed out that customers are essential for the development of new services or product, patients can also play this role. This all the more important, as customers’ needs and requests are often a fruitful source for innovations. One motivation for the phenomenon, that customers invent new products or services is caused by the fact some specific needs that are not fulfilled by the market. This may also be the reason, why patients develop ideas for other patients and of course themselves. However, online communities can be an appropriate instrument for patients, who invent products and services in order to meet their specific needs.

Customers’ ideation in such online communities most often happened in an uncontrolled and unstructured way, because existing discussion forums technologies in such online communities primarily focus on supporting discussions and the exchange of information. The real core of a generated idea is not in focus and therefore is not usually visible and tangible. Therefore, in this research in progress paper we introduce a modular extension of existing discussion forums in patient communities that allows a systematic ideation among patients to better leverage the innovative potential of patients. The developed module "Ideenschmiede" for the systematic creation and expansion of ideas is based on the open innovation paradigm, which is set out below.

2. The open innovation concept

Open innovation is a concept that has its origins in the high tech industry and has increasingly found in other sectors. (Chesbrough et al., 2006) describe open innovation as a paradigm for the systematic opening of a companies’ innovation process. Innovations can take place in accordance with this approach in the form of an "outside-in process," "inside-out process" or "coupled process". At the outside-in-process the generation of knowledge and ideas takes place outside of the company, which will be developed internally by the company and

transformed to a marketable output. In contrast the inside-out process commercializes knowledge, which has its origin within the company, externally. Thus the basis for inventions and innovations do not necessarily have to occur where they are used. Cross-industry innovations bring ergo an extra profit when the technology is already established in their own market and represents an innovation in other industries, where it is licensed. If these two processes are combined, then it is called a "coupled process" (Reichwald & Piller, 2009). To what extent an organization designs each core processes or rather uses it, is variable. For the realization of open innovation instruments such as innovation communities, toolkits, lead-user method and ideas competitions are available.

A key principle of open innovation is crowd sourcing (Ebner et al., 2009), which is based on the so-called "wisdom of crowds" principle. The "wisdom of crowds" can be used within the open innovation approach in order to develop ideas for new products and services with the involved actors and to transform these ideas into concrete innovation projects. The change of the user behavior, from a pure consumption towards an active collaborative creation of content, which took place with the rise of Web 2.0, supports the involvement of stakeholders in the innovation process to face unresolved research questions or problems (Back et al., 2009).

These concepts "wisdom of the crowds" and "open innovation" transferred to the healthcare industry leads for example to IT-based ideas communities for patients. One advantage is the easy access to such communities, because they are not bounded to a certain location. Moreover the usage is time-independent and allows thus a continuous knowledge exchange and share of experiences made with treatments, doctors, medical equipment, nursing services, etc. (Hartmann et al., 2010). Furthermore, patients often use the internet in order to look out for health information actively. So patients, who have received their diagnosis for example, look on the Internet for further information regarding a certain diagnosed disease, appropriate treatments et cetera. Thus, patients as well as their relatives have a wide range of expertise. This information can be used for the optimization of existing or the development of new healthcare products and services. In addition, such information can also be used in order to develop ideas which improve the everyday life of patients and support a self-determined existence.

Apart from that (Borasio & Pongratz, 1997) revealed, that the participation of (cancer) patients in online communities leads to a higher self-esteem. Patients are also less depressed

and anxious. Furthermore they feel better cared for their needs. Patients who suffer from severe or fatal disease are characterized in contrast to patients with less severe diseases from the fact that they deal intensively with their illness and they are strongly committed to a community (Leimeister & Krcmar, 2006).

Based on this motivation, the concept for the module "Ideenschmiede" is designed on the one hand to tap the innovation potential of patients and on the other hand to empower other patients to help themselves in which existing patient communities are supplemented by functions for a systematic development of ideas. By strengthen this principle the quality of life of patients respectively of ALS patients can be improved (Leimeister et al., 2005).

3. Research Methodology

As there is only little academic information systems research about the research object “development of ideas in online communities for patients”, deduction from theory is hardly possible. We therefore designed our research as Action Research according to (Baskerville, 1999) action research cycle (see Figure 1). Thus, while designing the novel, socio-technical artifact in form of a modular extension of online community for patients, we can continuously improve the artifact as we learn. Action research is defined by (Rapoport, 1970) as follows: “Action research aims to contribute both to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint collaboration within a mutually acceptable ethical framework.”.

Thus the structure of the next sections follows this approach. Within the phase “Diagnosing” we present a comprehensive problem description of a concrete online community for patients – namely the community behind the ALS forum of the DGM e.V. Additionally, in the phase “Action Planning” we developed a concept for a modular extension of online communities based on the problem description. Within the phase “Action Taking” we describe how we piloted the Ideenschmiede within the ALS Community. After that we present the gained preliminary evaluation results in the phase “Evaluating” and summarize our approach as well as the results in the “Specifying Learning” phase.

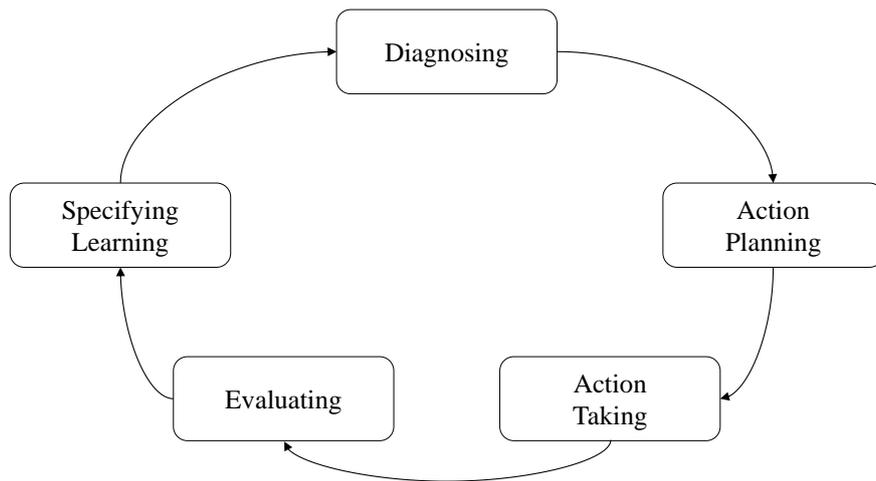


Figure 1: Action Research Cycle (Baskerville, 1999)

4. Diagnosing

The module “Ideenschmiede” was developed in cooperation with the German association for Muscular Dystrophy (DGM). In the wake of their service offering the DGM supports amongst others people, who suffer from amyotrophic lateral sclerosis (ALS).

4.1. Case Background

ALS is a degenerative disease of the central nervous system and leads by an average of three years to death. ALS is a seldom neurological disease, where the reasons for this disease are not known yet and where no cure is available until now (Borasio & Pongratz, 1997). Because of the disease functional disturbances of the nerves emerges which causes deficiency of the musculature. Thus the patients mostly suffer from chewing and swallowing difficulties (Borasio & Pongratz, 1997).

4.2. Problem Description

As a part of their website the DGM runs an internet forum about ALS. In this forum people that suffer from ALS or people who know people having ALS can communicate with each other. They use the forum to exchange information about ALS, they discuss about personal problems caused by ALS et cetera. So there is a wide range of topics addressing ALS starting from general discussions about how ALS patients handle the disease up to passing personal experiences made to other forums’ user.

Apart from that the users of the ALS forum share ideas. These ideas focus on how the all-day-life of ALS patients and their relatives and friends could be improved in order to guarantee a maximum of a self-determined life. That is why users mostly share information about tools and how they can be adapted to meet the specific requirements of ALS patients. So the ALS forum also contains information about self-developed or adapted tools. That links to the paradigm shift towards to the so called active patient. Nowadays patients are not anymore just a passive stakeholder within the healthcare sector. Rather they become an active partner and influence their treatment process. However the current technical platform as well as the underlying structure of the ALS forum is not suitable at all for having an active exchange of ideas and a collaborative development of ideas created by ALS patients. That is why such ideas often receive no consideration. To be more specific at this point the following section shows the structure of a typical internet forum and thus of the ALS forum as well in more detail.

The major structural element of forums is the thread. Users who are registered are allowed to define new threads addressing a self-determined topic. Within a thread all registered users can post their answers regarding the thread topic. Normally the posts are ordered by their publishing date, while the oldest post is the first one. If a thread consists of a big number of users posts, these posts are distributed over several sites within this certain thread. This is the reason why new posts are not recognized by users, as the new posts are not visible at the front page of the thread. This effect is also known in the field of search engine optimization and search engine marketing. So nearly 87% of all users of Google Search only look at the first page of Google's hit list (BVDW, 2008). The other sides of the hit list are mostly ignored. With regard to the development of ideas, which are often developed iteratively and where the development largely takes place through intensive discussions, this effect not beneficial.

The users of the ALS forum are aware of this, which is why they tried to develop an appropriate structure in the forum. For instance, they created a specific thread regarding useful medical tools. So indeed, a first categorization of ideas is achieved, but the problem that ideas are often distributed over several pages still exists. A tracking regarding the development of the ideas is thus still very time extensive. Feedback, which is targeted at a specific idea in the thread, is also difficult to make. Summarizing this, there is a lack of collaboration. This is crucial, because collaboration has a significant impact on idea quality (Bretschneider, 2011). Therefore our developed concept has to provide measures that support a collaborative ideation.

Besides these aspects traditional forums such as the ALS forum misses the ability to evaluate ideas. An evaluation in terms of idea quality is therefore also difficult to realize.

5. Action Planning

The approach of a modular extension of the ALS forum of the DGM was elected to develop a solution for the identified problems in the ALS forum and to support the active development of ideas by the ALS patients and their relatives. This modular expansion, which is called "Ideenschmiede", equips the ALS community forum with additional features that enables a structured and collaborative development of ideas. The "Ideenschmiede" is thus not a platform which is built around a new community. Rather it is an additional tool that supports the existing community of the ALS forum for idea development.

The module "Ideenschmiede" uses functions, which come to use in ideas communities such as "Tchibo Ideas" or "My Starbucks Ideas", and adapts them to the needs of ALS patients. Therefore the module "Ideenschmiede" focuses exclusively on the development of ideas around the topic ALS. An essential element of the "Ideenschmiede" is the evolution of ideas by other users, because collaboratively developed ideas have a higher quality than ideas developed by a single person. Thus all registered users of the "Ideenschmiede" have the opportunity to change an existing idea directly. This feature is similar to the editing of articles in wikis like at Wikipedia. So the users are able to develop the core of the idea further and will not get lost in the comments of an idea, which is one of the highlighted problems mentioned above. The changes made to the idea can be stored in a version history, so that the original author of the idea can delete any changes, if it is necessary. Furthermore the development of an idea is due to the version history transparently represented.

The consistent development of the construct "idea" is also supported through the fact, that on the home page of the "Ideenschmiede" the five most recent ideas are always visible as well as the recent user comments linked to a specific idea. In addition a so-called "idea space" is created in which the users of the "Ideenschmiede" can look for the published ideas using various filter criteria (e.g. date of submission of an idea, modification date of an idea).

The development of the "Ideenschmiede" was performed iteratively, so that several prototypes were developed and tested. Before the development of the prototype a systematic requirement analysis which analyzes the abilities, needs and preferences of the future users was applied. For doing so we conducted six telephone interviews and created an online survey

that was answered by 21 ALS patients and family members. In addition a semi-structured interview with a DGM representative was performed. We also attended an ALS discussion group (30 participants) and a muscle discussion group (20 participants) once. The results of the requirement analysis reveal that ALS patients have a high degree of intrinsic motivation. They also have an extensive expert knowledge and experience regarding ALS because of the daily struggles with ALS, which manifests itself in many ideas that possibly can make the everyday life ALS patients easier.

Furthermore our requirements analysis showed that the "Ideenschmiede" must be designed as simple as possible, as with the continuous progression of the ALS disease patients are becoming physically strongly restricted. Due to the fact, that this disease usually occurs between the age of 50 and 70, the default font size had to be enlarged several times until it was described by the ALS patients as adequate. Additionally, the users have the ability to adjust the font size individually, if the readability should not yet be given.

Another important adoption of the "Ideenschmiede", which resulted from the test of the platform with ALS patients, relates to the structure of an idea. Originally, an idea consisted of the following structural elements: (1) title, (2) summary of the idea, (3) description of the idea, (4) tags describing the idea, (5) optional version information, (6) optional file attachments. Surprisingly the ALS patients did not differ between the elements "summary of the idea" and "description of the idea", as they described in the "summary" already the complete idea. Because of that and with respect to the fact, that the usage of a computer is very difficult for ALS patients as they have restricted motoric capabilities, we merged these two structural elements. In addition our regular user tests revealed that ALS patients are concerned about their anonymity. Thus only the first names of the users are shown in the "Ideenschmiede".

This described concept shall provide a helpful and concrete solution for the community of the ALS forum by enabling the community to develop ideas collaboratively in a systematic manner.

6. Action Taking

The module "Ideenschmiede" was launched and connected with the ALS forum on 21st November, 2011 (see Figure 2). We actively informed the ALS community about the launch of the "Ideenschmiede" by using press releases, article in a regional newspaper and postings

in the ALS forum of the DGM. We furthermore stimulated the ALS community, as we introduced a so called “theme week”. This theme week was entitled: “How can I tell my relatives that I am diagnosed with ALS?”. The ALS community was encouraged to develop ideas regarding this topic collaboratively by using the “Ideenschmiede”. Thus we actively intervened in our object of research, which is a key characteristic of Action Research (Susman & Evered, 1978).

Furthermore we welcomed every new registered user of the “Ideenschmiede” by sending a personalized message. Within this message we informed about the intention of the “Ideenschmiede”, about the current theme week et cetera and who is responsible for this project. We also invited them to evaluate published ideas and to send us feedback, if there are any questions regarding the “Ideenschmiede” in order to optimize our developed concept. Thus we collaborated with the users particularly with the ALS patients, which is another characteristic of Action Research according to (Susman & Evered, 1978).



Figure 2: The developed module "Ideenschmiede" (www.dgmideenschmiede.de)

7. Evaluating

With respect to the Action Research Cycle the evaluation is the next step. As we present research in progress, this section presents first descriptive data to give some first impressions regarding the proof of concept.

Since the launch of the "Ideenschmiede" on 21th November, 2011 150 users, who have developed overall 46 ideas around the topic of ALS, have registered. Of these ideas are 35 collaboration ideas – these ideas can be further developed by other registered users. In contrast there are 11 so-called individual ideas, which cannot be further developed by other users. 14 of the 46 shared ideas were reviewed by the users of the "Ideenschmiede" once. Thus 30,4% of all ideas are reviewed by the community. In addition 69 comments were generated from users and 37-times ideas were rated by the users. So we can conclude that these collaboration ideas fulfill the requirements of the collaboration principle. To be more precise, we can assume that all participants of a collaborative developed idea have a shared understanding regarding the respective problem definition. Moreover we can also assume that there was a minimum of communication amongst the collaborators involved (Bretschneider, 2011).

Apart from that, we performed first analyses regarding the user behavior. For doing so we used the analyzing tool Piwik 1.7. A first analysis of the recorded data shows, that since the launch the "Ideenschmiede" has 3727 unique visits from registered users. 2966 visits are visits from registered users in Germany. 441 identified visits come from users in Switzerland while 252 visits come from the U.S. – 68 visits are made from other countries. Per visit about 7 actions were executed. The average time spent on the "Ideenschmiede" is about 7 minutes per user.

The reason for this relatively high residence time is probably due to the fact that the users are mostly highly limited in their motor capability because of the ALS. That is why they use their computers slowly. So they need more time to get an overview of the current content or to publish their own content as healthy users. Furthermore the majority of registered users visited the "Ideenschmiede" on a regular basis, as 2424 of 3727 visits are returning visitors. These users are also mostly those users, who whether publish regularly new ideas, develop existing ideas further or comment ideas.

To present a comprehensive and rigor evaluation we will evaluate the quality of the ideas published at the “Ideenschmiede” by an expert jury. These results will be compared with the evaluated ideas published in the original ALS forum of the DGM e.V. If the quality of ideas generated at the “Ideenschmiede” is higher, we then can evidence that this concept works. Furthermore we are able to conclude, that patients can be “user innovators”, as (Lüthje, 2004) called them.

8. Discussion & conclusion

To summarize this research, we developed a module called “Ideenschmiede”, which extends existing online patient communities in order to support the collaborative and systematic idea development. Online communities are nowadays a vital place for patients, where they can communicate with each other about diseases, therapies et cetera. But they also develop and share innovative ideas, which shall make their all day life easier. To structure this process we expanded an online community by using the module “Ideenschmiede”. Our approach was based on the action research cycle by (Baskerville, 1999). According to this approach we started with the phase “Diagnosing” followed by the phase “Action Planning” in which we developed the concept for the module called “Ideenschmiede” based on the problem description gained in the phase “Diagnosing”. In the phase “Action Taking” we iteratively developed and implemented the module.

The modular expansion eliminates the necessity of creating a new online community, as the module “Ideenschmiede” can be connected with existing online communities. Thus there is no need to implement a whole new community or IT platform. Consequently the community provider can extend their communities with little effort. The principle functionality of this approach was checked using the community of ALS patients organized in the ALS forum of the DGM. For doing so the development of this concept including the module "Ideenschmiede" followed the action research cycle by (Baskerville, 1999) (see Figure 1). Starting with the actual analysis of the particular requirements of ALS patients, we created and implemented iteratively the concept of the "Ideenschmiede". The next step will be a comprehensive evaluation of the quality of the generated ideas.

The users develop ideas and proposals that aim directly to ALS affected people in order to support the concept “help for self-help”. Furthermore the wide experiences and expertise of ALS patients is reflected in the submitted idea, which shows the innovative potential living in ALS patients. Compared to the ALS forum of the DGM, in which ideas are shared next to

general information regarding the ALS disease itself, the module "Ideenschmiede" focuses strictly on the collaborative development of ideas. The presented preliminary evaluation results (see section 7) show also that the offer of the joint development of ideas is obviously accepted by the users and, it can be stated that the presented concept basically works.

However, it must be pointed out that the obtained results have been reached in the context of online communities for patients diagnosed with the deadly nerve disease amyotrophic lateral sclerosis (ALS). These patients are characterized by a high intrinsic motivation, which can be a reason for the intensive usage of the "Ideenschmiede". Therefore the developed concept must be transferred in a next step to online communities consisting of users with a different personal history in order to make generalized statements about the concept of the "Ideenschmiede". Furthermore the evaluation has to be finished in the next step to evidence our developed concept.

References

- Back, A., Gronau, N. and Tochtermann, K. (2009) *Web 2.0 in der Unternehmenspraxis: Grundlagen, Fallstudien und Trends zum Einsatz von Social Software*. München: Oldenbourg.
- Baskerville, R. L. (1999) Investigating information systems with action research. *Commun. AIS*, **2**, 4.
- Blanchard, A. (2004) The Effects of Dispersed Virtual Communities on Face-to-Face Social Capital. In: M. Huysman and V. Wulf, eds. *Social Capital and Information Technology*: MIT Press.
- Bohnet-Joschko, S. and Bretschneider, U. (2008) Coping with Chronic Illness Online: The Case of Patients' Internet Communities For Diabetes Mellitus and Multiple Sclerosis. *The Electronic Journal for Virtual Organizations and Networks (eJOV)*, **10d**, 1-7.
- Borasio, G. D. and Pongratz, D. E. (1997) Gedanken zur Aufklärung bei amyotropher Lateralsklerose (ALS). *Der Nervenarzt*, **68**, 1004-1007.
- Bretschneider, U. (2011) *Die Ideen Community zur Integration von Kunden in die frühen Phasen des Innovationsprozesses - Empirische Analysen und Implikationen für Forschung und Praxis*. München.
- BVDW. (2008) BVDW Eyetracking Studie 2008. Düsseldorf: Bundesverband Digitale Wirtschaft (BVDW) e.V. & phaydon research+consulting.
- Chesbrough, H., Vanhaverbeke, W. and West, J. (2006) *Open Innovation: Researching a New Paradigm*: Oxford University Press.

- Ebner, W., Leimeister, J. M. and Krcmar, H. (2009) Community Engineering for Innovations - The Ideas Competition as a method to nurture a Virtual Community for Innovations. *R & D Management*, **39**, 15.
- Hartmann, M., Prinz, A., Hirdes, E., Görlitz, R., Rashid, A., Weinhardt, C. and Leimeister, J. M. (2011) Web 2.0 im Gesundheitswesen – Ein Literature Review zur Aufarbeitung aktueller Forschungsergebnisse zu Health 2.0 Anwendungen *Wirtschaftsinformatik Konferenz (WI) 2011*. Zürich, Schweiz.
- Hartmann, M., Prinz, A. and Leimeister, J. M. (2010) Open Innovation im Healthcare - Systematische Entwicklung von Ideenwettbewerben am Beispiel von Patienten mit amyotropher Lateralsklerose *40. Jahrestagung der Gesellschaft für Informatik 2010: Service Science – neue Perspektiven für die Informatik*. Leipzig, Germany.
- Leimeister, J., Krcmar, H., Horsch, A. and Kuhn, K. (2005) Mobile IT-Systeme im Gesundheitswesen, mobile Systeme für Patienten. *HMD - Praxis der Wirtschaftsinformatik*, **41**, 74-85.
- Leimeister, J. M. (2005) *Virtuelle Communities für Patienten - Bedarfsgerechte Entwicklung, Einführung und Betrieb*. Wiesbaden: Dt. Univ.-Verl.
- Leimeister, J. M. and Krcmar, H. (2006) Community-Engineering: Systematischer Aufbau und Betrieb Virtueller Communitys im Gesundheitswesen. *Wirtschaftsinformatik*, **48**, 12.
- Lüthje, C. (2004) Characteristics of innovating users in a consumer goods field: An empirical study of sport-related product consumers. *Technovation*, **24**, 683-695.
- Rapoport, R. (1970) Three dilemmas of action research. *Human Relations*, **23**, 499-513.
- Reichwald, R. and Piller, F. (2009) *Interaktive Wertschöpfung*. Wiesbaden, Germany: Gabler.
- Susman, G. I. and Evered, R. D. (1978) An Assessment of the Scientific Merits of Action Research. *Administrative Science Quarterly*, **23**, 582-603.