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Angelika Bullinger

Chemnitz University of Technology & University of Pennsylvania

Matthias Rass

University of Erlangen-Nuremberg

Kathrin Moeslein

University of Erlangen-Nuremberg

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TOWARDS OPEN INNOVATION IN HEALTH CARE

Bullinger, Angelika C., Chemnitz University of Technology & University of Pennsylvania, Erfenschlager Straße 73, 09125 Chemnitz, Germany, awi@tu-chemnitz.de

Rass, Matthias, University of Erlangen-Nuremberg, Lange Gasse 20, 90403 Nuremberg, Germany, matthias.rass@wiso.uni-erlangen.de

Moeslein, Kathrin M., University of Erlangen-Nuremberg, Lange Gasse 20, 90403 Nuremberg, Germany, kathrin.moeslein@wiso.uni-erlangen.de

Abstract

Many countries face severe challenges in health care, especially soaring costs. Innovative products and services are needed to help increase the quality of care and to reduce costs. In the field of rare diseases, which often is not attractive economically, the situation is even more serious. Building on extant research on open innovation, we use a design science approach to study an open innovation platform for rare diseases. Like many other open innovation practices, e.g. innovation communities and innovation contests, the platform is based on modern information and communication technologies, and is designed to be accessible from anywhere and anytime, thus supporting asynchronous interaction between the locally dispersed participants. Analysis of participation details, submitted innovative concepts, and content of communication shows acceptance by patients and other relevant stakeholders, e.g. family members, caregivers, and health care professionals. Activity on the platform, i.e. almost 200 innovative submissions, 800 comments, and more than 1,800 personal messages, is found to be helpful for collaborative innovation and emotionally supportive for participants. Generalizing from the special field of rare diseases, implications concerning the suitability of open innovation approaches in health care from a theoretical, methodological, and management perspective close the paper.

Keywords: open innovation, health care, rare diseases, integration, stakeholders

1 Introduction

Health care costs are soaring in several first world countries, such as the U.S., France, and Germany, consuming as much as 10 percent of GDP while increasing at about twice the rate of economic growth (OECD, 2010). This is partially due to an ongoing demographic change. In particular, Western countries witness diminishing birth rates and an increasing life expectancy (United Nations, 2009). Rapidly rising costs might be justified by increasing effectiveness or higher quality of care. However, in the U.S., for example, an estimated \$700 billion out of the \$2.5 trillion health care budget is considered wasted due to inefficiencies, overtreatment, and error (Kelley, 2009). Accordingly, higher spending does not per se lead to better outcomes for patients. This development calls for reconsideration of health care budgets and improvement of quality of care for patients. The health care sector, with its heterogeneous set of stakeholders, thus needs to put additional emphasis on *innovation*.

In the particular field of *rare or orphan diseases*, the situation is even more serious. Following the European Union Orphan Drugs Regulation (Eurordis, 2009), a disease is defined as rare if it affects less than 5 out of 10,000 people. From the low prevalence follows scarce medical knowledge, inconsistent therapy concepts, deficient operational guidelines, and problems in allocating responsibilities between healthcare professionals and patients (Bullinger et al., 2012). As this field often is not attractive economically, the private sector's investments in research and development are limited (Denis et al., 2010). Conversely, those affected by a rare disease often gather large amounts of medical and experiential knowledge on their disease (Boote et al., 2006; The Lancet, 2008). They often become active in self-help organizations or even establish new ones (Borkmann, 2007). During their activities, patients and family members display innovative capabilities. For instance, a mother of a young woman with vaginal adenocarcinoma proposed to health professionals that it might have been caused by diethylstilboestrol (Boote et al., 2002). This example, seen from the perspective of researchers in open and user innovation, entail that patients and their immediate environment might become knowledgeable, intrinsically motivated experts. Their advanced market need and additionally, their important solution knowledge (von Hippel, 1986) hold important potential to develop novel products and services for the field of health care.

However, the health care sector at large has been quite hesitant to integrate different stakeholders in the development of novel solutions. While an increasing number of *web 2.0 health platforms* (Hartmann et al., 2011; Oh et al., 2005) are available for the growing number of Internet users that go *online for health-related topics* (Kummervold et al., 2008), these mainly focus on the *distribution of health information*.

In sum, rising costs for health care, a need for effective product and service innovation, and the online availability of knowledgeable experts for health care topics, calls for a solution that goes beyond current, informative *health 2.0* platforms. This paper reports on a design-oriented approach to fill this gap by designing, developing, and evaluating an IT-based *open innovation platform* for rare diseases. Rare diseases are chosen as a unique field, which requires highly specific knowledge to develop novel solutions. Generalizing from this specialized field, we draw conclusions for the broad field of health care. The platform, targeting German stakeholders of rare diseases, has attracted more than 1,000 participants who have submitted almost 200 proposals, 760 comments, and 1,800 personal messages in the first four months of runtime. We show that the *open health platform* is well accepted by stakeholders in the field of rare diseases to interact, establish a sense of community, and most importantly, to submit, discuss, and collaboratively develop innovative solutions.

Research presented in this paper has the following goals:

1. From a theoretical perspective, we extend open innovation research by providing a first proof of concept on the possibilities of *open innovation in the field of rare diseases* as a way to increase integration of stakeholders.

2. From a methodological perspective, our study draws on a *design science* research approach to *design, develop, and evaluate* an open innovation platform for rare diseases.
3. From a practical perspective, our research shows opportunities and provides implications of opening up innovation processes in *health care* to interested and knowledgeable stakeholders.

Subsequent, extant knowledge on the health care system and open innovation are introduced. We then describe our research methodology and the empirical field. The final sections present the results of the evaluation of the open innovation platform and a concluding discussion.

2 Open Innovation in Health Care

2.1 Characteristics of the Health Care System

The global health care sector, which represents about eight per cent of the global economy, consists of very diverse stakeholders with sometimes conflicting interests (Kennedy & Berk, 2011). Five major groups can be distinguished: 1) *regulators*, e.g. national or regional regulatory committees; 2) *suppliers*, e.g. pharmaceutical and medical technology companies; 3) *payers*, e.g., statutory or private health insurances; 4) *care givers*, e.g., doctors, nurses, and other health professionals who provide care; and finally, 5) *patients and their families* as beneficiaries of care and informal care givers.

In terms of numbers, *patients and their families* are the largest group. They have gained significant experience, either through their own health records or through the ailments of relatives or friends. Nevertheless, health care suppliers and other stakeholders have been reluctant to open their innovation processes to patients and other interested and knowledgeable stakeholders like care givers, organizations that represent the interests of people who use health services, members of the public who may be the potential recipients of health promotion plans, – and persons generally interested in questions of health care (Boote et al., 2006; Steininger et al., 2009).

Instead of *integration* of stakeholders, the majority of existing *health 2.0 platforms* focuses on *information*. Popular examples of health-related websites are *WebMD*, *Yahoo Health*, and *Revolution Health*¹. These sites are mainly information resources for information seekers in the field of health care, ranging from general health advice to more detailed information, e.g. on lung cancer. Articles are typically reviewed by one or more physician editors before publication. *Revolution Health* also uses patient chat groups to disseminate information. More *community-oriented* health platforms often unite established patient support groups and rely on interaction among participants. For instance, *Daily Strength* and *CureTogether*² focus on sharing knowledge, experience, and mutual support in discussion boards. Building on *exchange* of medical data among participants, *PatientsLikeMe*³ allows the upload of medical conditions to create a structured personal health profile. Metrics and graphs then allow for monitoring of treatments and the state of health. The for-profit platform allows other companies to reach out to patients, e.g. for trial recruitment, education purposes, or sentiment analysis. Summarizing, the main goal of these health 2.0 platforms is the distribution and exchange of information. Innovative output is not regarded as an important element.

2.2 The Concept of Open Innovation

Today, an organization's ability to recognize and exploit useful knowledge from outside sources is seen as critical to its innovative capabilities (Cohen & Levinthal, 1990). While external sources of innovation may not completely replace internal sources, they are important to complement them. Thus, organizations can no longer act independently, but have to connect with different actors to acquire

¹ <http://www.webmd.com>, <http://health.yahoo.net>, <http://www.revolutionhealth.com>

² <http://www.dailystrength.org>, <http://www.curetogether.com>

³ <http://www.patientslikeme.com>

external ideas and resources that help them to remain competitive (Chesbrough, 2003; Dahlander & Gann, 2010). This approach of opening up traditionally closed innovation processes towards external actors has been coined by Chesbrough (2003) as ‘open innovation’.

Since the 1980s, scholars have highlighted the importance of users that actively take part in innovation activities (von Hippel, 1986). Recent studies confirm the importance of users as a source of innovation (Bogers et al., 2010; Fuchs & Schreier, 2011). In many cases, they are able to use their unique knowledge and expertise to devise cost-efficient innovations that can satisfy their own demands (Bogers et al., 2010). This has been found for the sports industry, e.g. in mountain biking (Luethje et al., 2005) or sailing (Raasch et al., 2008), where important innovations have been developed by users. Researchers have also found that in voluntary special-interest communities, e.g., a handicapped cycling community, users tend to support each other by revealing innovation-relevant knowledge as well as self-devised innovations without expecting monetary consideration (Franke & Shah, 2003). Studies on open source software stress the importance of mutual support in user innovation activities (Bagozzi & Dolokia, 2006; Franke & Shah, 2003). Users may not only conceive innovative concepts, but also be able to commercialize their solutions without a supporting manufacturing firm (Bogers et al., 2010).

Many companies have recognized the potential of harnessing the users’ knowledge base and have begun to actively integrate them into their innovation activities. While poor connectivity has been a reason in the past that users were restricted to a passive role in new product development, today’s technologies enable cost-effective integration of users in the innovation process (Nambisan, 2002). Organizations use virtual communities to foster user-to-user support as well as user-driven innovation (Nambisan & Baron, 2010). Another innovation practice making use of the global accessibility of online platforms which also support asynchronous communication, are online innovation contests, in which participants compete for an award in solving an innovation-related task defined by an organizer (Boudreau et al., 2011). In many cases, these platforms also enable interaction among participants and thus support cooperative development of novel solutions (Bullinger et al., 2010; Hutter et al., 2011).

2.3 First Cases of Open Innovation in Health Care

In the field of health care, initiatives like the Archon Genomics X Prize⁴ demonstrate some principles of open innovation. The Archon Genomics X Prize is an open call, awarding \$10 million to the team that first builds a device that is able to rapidly and economically sequence 100 whole human genomes at an unprecedented level of accuracy. While this initiative holds some similarities to an innovation contest, the level of task complexity reduces potential participants to *scientists* who are already working in medical research. This limitation in participation can also be observed for another kind of open innovation approaches in health care, taking place especially in the pharmaceuticals and biotechnology industry. Here, industry-industry and industry-university collaboration in innovative processes are considered as crucial and also are commonly practiced (Powell et al., 1996; Tapon & Thong, 1999).

Concerning *other potential participants* in open health processes, there is anecdotal evidence showing *patients’* ability to develop sophisticated medical solutions. For instance, a British engineer diagnosed with Marfan syndrome designed his own heart implant which was better than other solutions and has later been implanted in 23 other patients (Zolfagharifard, 2011). This ability to come up with a medical solution is not limited to *patients* themselves. A high school girl in Maryland devised the Pain Free Socket, a prosthetic device that is intended to ease phantom limb pain in amputees, to help her father, a disabled veteran. The device, currently a fourth-generation prototype, has currently a patent application pending (Laporte, 2011).

⁴ <http://genomics.xprize.org>

This kind of user – someone who has a certain need earlier than others and also has the knowledge to find a solution that can satisfy the need – is termed *lead user* in innovation literature (von Hippel, 1986). Given the high intrinsic motivation of patients, their families, and other potential stakeholders in health care to acquire knowledge and find solutions to their problems, a broad base of (lead) user innovators in the field of health care can be estimated. While only few of them might be able to find solutions that can cure a disease, their knowledge and understanding of everyday needs might help to develop innovative concepts.

In order to provide patients and other stakeholders with the possibility to innovate, an IT-based open innovation platform for health care seems promising for three reasons. First, it has the potential to bring together the diverse stakeholders in the field of health care and to align their interests. Second, the platform fills a gap in existing health 2.0 platforms as it focuses on development of innovative solutions. Third, by design, development, and evaluation of a solution for *rare diseases* which are considered a particularly difficult context, conclusions for the broader field of general health care can be drawn.

3 Method

3.1 A design science approach

To enable interested and knowledgeable stakeholders to collaboratively develop novel products and services, and thus increase integration of stakeholders in health care, a design-oriented approach is applied to create an IT-based *open health platform*.

In design-oriented research, *artifacts* – artificial, man-made things – are the central objects of research (Simon, 1998). They are specially crafted in order to fulfill certain purposes and goals. Researchers then assess results by determining the degree to which the artifacts achieved the predetermined goals. Possible artifacts in IS research include: constructs, models, methods, and instantiations (March & Smith, 1995). The aspired research outputs we describe in this contribution are a *construct*, i.e. vocabulary to define problems and solutions – the concept for an open innovation platform for health care – and an *instantiation*, i.e. the realization of an artifact in its target environment – the open health platform for rare diseases *GemeinsamSelten*.

In contrast to the well-defined and broadly accepted approaches found e.g., in the social sciences, there is no agreed upon procedure for conducting design-oriented research. However, there is consensus on the basic structure of design-oriented research (cf. Hevner et al. 2004; March & Smith 1995; Takeda et al. 1990). Since design-oriented research follows a problem-solving paradigm, the first step is to *identify* the problem and its context. Based on that insight, a possible solution is *designed*, defining the goals for the artifact and the desired outcome when putting the artifact to use. This artifact is then *implemented* in the next step of the process and put to use in the context it was designed for. Subsequent, the artifact is *evaluated* and conclusions are drawn and documented during *deduction*, e.g. as new input for another iteration. Table 1 below shows the research process and indicates where results of each step can be found in sections of this paper or in a different publication, respectively.

Research Step	Description of research step	Section/ Publication
Problem identification	<ul style="list-style-type: none"> Theory-driven and empirically identified need for open innovation platform for health care Research goal: proof of concept to increase integration of stakeholders in <i>open innovation platform for field of rare diseases</i> 	1 Introduction 2 Open Innovation in Health Care

Design proposition	<ul style="list-style-type: none"> • Theory-driven development of preliminary design • Discussion of preliminary design with future users, i.e. patients and family members, representing different rare diseases 	Design proposition is the focus of Adamczyk et al. (2011).
Implementation	<ul style="list-style-type: none"> • Instantiation, i.e. <i>GemeinsamSelten</i>, of ... • Construct, i.e. the concept of open health platform 	3.2 <i>GemeinsamSelten</i>
Evaluation	<ul style="list-style-type: none"> • Assessing <i>acceptance</i> of the open health platform by stakeholders (details on participants) • Assessing (innovative) <i>activity</i> on the platform (details on submissions and content of communication) 	4 Evaluation of the Open Health Platform
Deduction	<ul style="list-style-type: none"> • Implications for the next instantiation of <i>GemeinsamSelten</i> • Implications for <i>open innovation in health care</i> 	5 Discussion

Table 1. Process steps followed in this research (adapted from Takeda et al., 1990)

While the paper covers nearly all process steps of the design science research process, the focus is on the research step ‘evaluation’ which assesses acceptance by and activity of the participants.

3.2 *GemeinsamSelten*

*GemeinsamSelten*⁵ is a German⁶ online platform designed to attract and activate stakeholders in the field of rare diseases, integrating them into the development of new products and services in health care. Going beyond existing self-help groups that typically focus on single diseases, the platform addresses *all* rare diseases. This setup is chosen because, across the great variety of rare diseases, patients and their families are often confronted with similar challenges (Bullinger et al., 2012). Furthermore, *GemeinsamSelten* explicitly invites interested people with diverse backgrounds, e.g. engineers, product managers, or students from different disciplines. From the stage of *design proposition*, representatives of different rare diseases (patients and family members) have been integrated in the design process to ensure additional benefit (Adamczyk et al., 2011).

GemeinsamSelten has been set up as an online platform to fulfill two central requirements of patients with rare diseases: access from everywhere and asynchronous interaction. Due to the rare character of the diseases, patients are often at large distances from each other; a condition often aggravated by restricted mobility. In addition, the health condition and treatments of participants interrupt their continuous presence on the online platform. The possibility to track discussions, e.g. after hospitalization, is hence a crucial requirement.

The *concept* of the open health platform is divided into three interlinked areas: (1) a *community area* where users a) can have their own public profile containing personal and health data as well as provide information on health insurance, doctors, and drugs, and b) are presented with information on new members, member activity, platform-related news, and more; (2) a *problem area*, where users can post general questions as well specific everyday challenges; and (3) a *solution area*, where users can contribute innovative concepts for health care. Submitted problems and solutions may be outlined in plain text as well as in attached text, picture, audio, and video files. Concerning *interaction* among participants, there are numerous possibilities in each area. In the *community area*, users can directly communicate with other participants by leaving a message on their personal pin board. Furthermore, users can discuss problems and solutions of other users. In the *problem area* and in the *solution area*, users can evaluate, link and comment on problems and solutions submitted by others. The instantiation *GemeinsamSelten* has been realized according to this concept.

⁵ The German name of the community ‘*GemeinsamSelten*’ approximately translates to ‘RareTogether’.

⁶ The platform is moderated in German, but accessible worldwide.

Until late November 2011, the platform launched in late March 2011, had attracted more than 160,000 unique site visits and more than 1,100 registered users, who contributed almost 200 submissions, more than 800 comments on these submissions, and sent more than 1,800 direct messages.

4 Evaluation of the Open Health Platform

In design science research, evaluation tests the soundness and suitability of the artifact, focusing on relevance of built systems (Hevner et al., 2004). For the evaluation of the concept of the *open health platform* for rare diseases, we chose an *observational method (case study observation)* out of the five evaluation methods of design science in IS research (Hevner et al. 2004).

Data collection for evaluation covered the complete, anonymized *log files* of the platform *GemeinsamSelten*, *personal messages* exchanged between participants and *comments* on problems and solutions. Log files cover *problems, solutions*, qualitative as well as quantitative measures of comments and personal messages, which were tracked chronologically. Comments were additionally logged with the problem or solution they were submitted to, and with the participant submitting this comment. Personal messages were logged with the submitting and the receiving participant alike. Data was gathered from March to June 2011.

4.1 Participants

At the time of data collection, the platform had attracted 803 participants, i.e. patients and other interested stakeholders. Participants have very diverse professional backgrounds, e.g. nursing, engineering, business administration, medicine, and information systems. During registration, participants were asked to choose a role describing their association with rare diseases. Roles and their frequencies are presented in the table below.

Self-attributed role of participant	Absolute number	Percentage
Patient	358	44.58%
Interested person	283	35.24%
Family member	92	11.46%
Innovator	19	2.37%
Healthcare employee	16	1.87%
Researcher	16	1.87%
Supporter	9	1.12%
Caregiver	5	0.62%
Physician	5	0.62%
<i>Total (August 2011)</i>	<i>803</i>	<i>100.00%</i>

Table 2. Roles of participants

When choosing the roles *patient* and *family member*, participants could also indicate the rare disease most relevant to them. 191 (30%) of these participants reported affiliation with a total of 145 different diseases; 259 patients and family members did not disclose a disease. Drilling down the 145 diseases, 119 diseases are registered by one *patient* or *family member*, 17 diseases are registered by two *patients* or *family members*, three diseases are registered three times, three diseases are registered four times, one disease is registered five times, and two diseases are registered by six *patients* or *family members*.

Total registration, distribution of the participants across the different roles, and in particular the coverage of 145 rare diseases shows that *GemeinsamSelten* is suitable to attract a broad set of participants. We accordingly judge adoption of the open health platform to be successful. From an open innovation perspective, the different roles and the represented 145 rare diseases represent a broad range of knowledge sources and different capabilities which can be combined to reach important innovation outcomes in the field of health care.

4.2 Submissions

The platform *GemeinsamSelten* has received 197 innovative submissions, among these 144 problem descriptions and 53 solution concepts. Table 3 below details submitted innovative solutions. To categorize solutions, three raters independently evaluated them and afterwards jointly discussed their ratings to resolve discrepancies.

Solution category	Details on category	Total	Percentage
Physical product innovation	Hardware products and technologies	16	30.18%
Virtual product innovation	Software applications for computers or mobile devices	17	32.08%
Service innovation	Services and organizational concepts	11	20.74%
Media innovation	Media coverage, information channels	9	17.00%
<i>Total (August 2011)</i>		<i>53</i>	<i>100.00%</i>

Table 3. Submitted innovative solutions

An innovation platform is first and foremost to be evaluated as suitable if it gathers innovations. In our field, 53 innovative solutions and 144 expressions of needs and requirements can be regarded satisfactory. The table above shows that nearly a third of submitted innovative concepts are *software* or other *virtual product* innovations, i.e. applications for computers and mobile devices. Runner-ups are product innovations (30%) which include many technological concepts. Furthermore, eleven concepts of novel services or improved delivery of existing services and nine submissions of innovative media concepts were submitted. Figure 1 below shows some examples:



Rare disease passport
(physical product)



Mobile Toilet (physical product)



Open Street Map for rare diseases
(virtual product)

Figure 1. Examples of submitted solutions

4.3 Content of communication

We analyzed communication content on *GemeinsamSelten* in order to better understand i) the motivation of the participants, and ii) the (innovative) content of their communication on the platform. To do so, we followed widely accepted analysis procedures for coding qualitative data (Ryan & Bernhard, 2000) and classified personal messages and comments with regards to content. Initial independent coding by two coders resulted in more than 300 first-order codes, e.g. 'providing detailed information; advocating own contribution; etc.'. These were then condensed in 26 second-order codes, e.g. 'defending contribution'. In a third step, twelve meta-codes were derived by summarizing: support, question, experience, information, attraction, platform, critique, comparison, evaluation, problem, own contribution, and usefulness. In the following, communication content of the open health platform is presented for *personal messages*, *comments on solutions*, and *comments on problems*.

Personal messages. At the time of data collection, 213 participants submitted 680 personal messages. We excluded the additional 774 welcoming messages by community members and community managers from the analysis. We found that mostly patients and interested persons are involved in personal messaging: Patients contributed 468 messages (68.8% of all personal messages), interested persons

another 67 messages (9.9%). Messages were mainly used to *support* other participants, e.g. by providing advice regarding medication, nutrition, or physicians. An exemplary comment providing advice is: “[...] check out the prohormones dehydroepiandrosterone (DHEA) and vitamin D.” (personal message ID 1084; *support*)

Participants also used personal messages to ask various *questions* in order to obtain *support*, to get in touch with participants suffering from the same disease, or to be informed about personal or medical details. For instance, one patient would ask: “[...] is there an expert for the Sudek syndrome?” (personal message ID1106; *information*)

Comments on problems. For the 299 comments submitted to problems, it is particularly remarkable that a set of 75 participants stands out as main contributors. 214 or 71.6% of all comments were posted by patients while this group accounted for 44.6% of all participants. This is not surprising as patients have the broadest knowledge on diseases and the highest intrinsic motivation to discuss submitted problems.

Comments on problems were used to provide *experiences*, to ask *questions*, and to share *information*, e.g. on medical centers. Providing own experiences and asking for advice would read for instance: „My son suffers from the Legg-Calvé-Perthes syndrome [...] and is bound to his wheel chair. [...] I would be so glad, if he could do anything more than only go to physiotherapy and swimming...” (comment ID 152; *experience, question*)

Comments on solutions. Comments on solutions cover more aspects than comments on problems, even though the total of comments on solutions is lower: A total of 28 participants has posted 67 comments, with participants who chose the role ‘patient’ submitting 43 (64.2%) and participants with the role ‘interested persons’ contributing 13 (19.4%) comments.

Content of comments encompasses codes presented above and included additional aspects. Participants used comments also to *evaluate* solutions of other submissions, e.g. in terms of usefulness. “In my eyes, this idea is generally a good approach. [...] But I think that it is rather difficult to handle it. Where do you keep the passport? If you had a patient involved in a car accident, first responders could barely invest precious time to search the accident victim’s pockets for such a passport [...]” (comment ID 34; *evaluation, critique, question*). Participants who had posted the commented solution then used comments to defend their own contributions, or to give more details, compare them with other solutions submitted to the platform or an existent solution on the market, and generally engage in a discussion on their submission.

It has been the goal of this research to support innovative interaction among diverse stakeholders. Extant research has found that a sense of community among the participants can lead to products and services, which are highly innovative (Bullinger et al., 2010; Franke & Shah, 2003; Hutter et al., 2011). Thus, the large proportion of *mutual support* found in the *communication content* on *GemeinsamSelten* is expected to foster the *collaborative orientation* of participants. Accordingly, the other contents of communication, e.g. sharing knowledge, providing experiences, and actually discussing innovative submissions, indicate collaborative innovative activities, which hold – or already realize – the potential for highly innovative outcomes.

5 Discussion

From a *theoretical perspective*, it has been the goal of our paper to extend open innovation research to health care. We show that our concept to integrate stakeholders in the field of rare diseases is feasible using open innovation practices. Establishment of an open health platform has enabled the collaborative development of innovative products, services and solutions by interested and knowledgeable stakeholders in the field. Compared to extant, mostly offline approaches (Boote et al., 2002 and 2006), our research on an open health platform shows a cost-effective and significantly fast possibility to enable the integration of stakeholders in health care research and development.

The open health platform *GemeinsamSelten* has been well adopted by diverse stakeholders representing 145 different rare diseases. While the majority of *participants* has attributed itself to the group of *patients* (45%), more than a third of total participants has registered as *interested person* (35%). This broad interest by the stakeholders of rare diseases in the open health platform confirms earlier findings. First, the tendency of Internet users to search health-related content online (Kummervold et al., 2008), and second, the possibility to cost-effectively integrate external sources into the innovation process (in the field of health care) by using modern technologies (Nambisan, 2002).

However, our findings go beyond extant knowledge: Regarding the *activity* on the open health platform, participants have shown that patients and family members with rare diseases are knowledgeable experts and hold an important amount of need information. Their different need information combined with expert solution information from other fields, has led to the *innovative output* of 144 challenges and 53 solutions. Solutions encompass 17 elaborated concepts for software applications, e.g. an open street map adaptation for rare diseases; 16 product or technology submissions, some as elaborate as the prototype for the mobile toilet; as well as 11 propositions for services and organizational concepts like a better care sharing network for patients with different rare diseases. The innovative results of the open health platform confirm our suggestion that development of novel products and services by a diverse set of innovators will be possible in health care – both for rare diseases and for the general field – as has repeatedly been shown in other areas (Bogers et al., 2010).

In addition to the innovative output, the participants engaged in *community-building* by exchanging supportive messages, information, and advice (cf., Bagozzi & Dolokia, 2006). The significant part of this exchange of experiences and knowledge on care giving holds the potential to increase quality of care as required by the patients. Participants have reported successful realization of solutions proposed by others – without the expensive qualification programs for nurses and their family members which are traditionally required for realization.

Along with the findings of recent research in open innovation (e.g., Bullinger et al., 2010), this orientation of the participants towards collaboration and collaborative development of products, services and solutions holds the potential of highly innovative output in the future. Future research should focus on this innovative output and investigate in detail the participants, their relationships, and the resulting degree of innovation. It seems worthwhile to examine who initiates and who continues discussions on problems or solutions, and whether some participants are more active in contributing comments than in initiating.

Going beyond the actual *activity* of collaboratively developing novel products and services, scholars have recently stressed the meaning of *social capital*, i.e. the value of a network of social relationships, for knowledge transfer and innovation outcomes (Rass et al., 2011; Rost, 2011). In the context of this paper, rich networks that offer relevant knowledge from diverse sources as well as social aspects, like e.g. trust and mutual support, play a very important role. This perspective thus might offer a fruitful avenue for future research on open innovation in health care.

From a *methodological perspective*, this study uses a *design science* research approach (Hevner et al. 2004; Takeda et al. 1990) to *design, develop, and evaluate* an open innovation platform for rare diseases. Given the results of the platform and the resulting positive evaluation of the artifact, the use of a design-oriented approach can be deemed suitable. However, this article presents a single case study that offers initial findings which have to be validated in other samples. Future research should thus, seek for other, comparable approaches and conduct a multi-case study or try to validate our findings in a large-scale quantitative analysis.

From a *practical perspective*, this research illustrates the potential of opening up innovation processes in health care. As has been shown for the sports industry (Luethje et al., 2005; Raasch et al., 2008), active and knowledgeable users come up with innovative solutions independent of established manufacturers. Accordingly, the first instantiation of the platform has been designed to operate independently of major players in the field of health care, medical engineering, and insurance. However, in the future, companies in the field might increasingly realize the potential of opening up their innova-

tion processes and taking advantage of the innovative potential of consumers by either harnessing the knowledge available in existing communities like *GemeinsamSelten* or by purposively establishing other, specialized or general, open health platforms.

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