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Patients as Innovators – The Development of Innovative Ideas with the Ideenschmiede

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Abstract. Online Communities for Patients (POC) are very interactive sites where patients communicate with one another about diseases, therapies and how to deal with diseases and about personal experiences they have had. They also develop and share innovative ideas that make their everyday life easier. However, this happens mostly in an unsystematic and uncontrolled manner, as IT-supported interaction and communication tools in POC do not typically meet the specific requirements of ideation. For this ideation process, we developed a module called Ideenschmiede, which extends POC to support the collaborative and systematic idea development. The evaluation of the published ideas shows that the concept of the Ideenschmiede leads to ideas with an above-average quality level, indicating that collaborative ideation may also work in the healthcare context.

Keywords: Online Communities, Ideation, User Innovators, Healthcare, Action Research

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 [1-3]. Members of online communities can interact anonymously and independently over time and space [4], about how they deal personally with their disease and how they can process their disease mentally. Participating in Online Communities for Patients (POC) helps patients to find solace and social assistance [5]. Increasingly, patients are using online communities to exchange and discuss ideas on innovations that enhance the daily life of patients.

One sees strong parallels in the context of products and services for the consumer market. [6] points out that customers are essential for the development of new services and products. Using the same logic, patients can also play this role. [6] notes that customers' needs and requests are often a fruitful source for innovations. This is because customers invent new products or services when they have specific needs that the market does not fulfil [6]. This context is transferable to patients who, along with their relatives, have a wide range of expertise resulting from having personal experience with diseases. Patients often have unfulfilled disease-related needs, especially in

the context of rare diseases. Hence, patients develop ideas for other patients and, of course, for themselves in order to improve their everyday life and to support a self-determined existence. These ideas can focus on how patients can “buy and use health-care” [7] or how they can use “technology to develop new products and treatments or otherwise improve care” [7].

Although we can find POC where ideation happens, this often happens in an uncontrolled and unstructured way. A major reason for this is the primary focus on the information exchange and discussion support in online communities. Working collaboratively on a concrete idea is not the focus of IT support for POC. IT tools in POC mainly support communication among patients, as in the case of an Internet forum. Nevertheless, collaboration is an important determinant for the development of high quality ideas, and it makes knowledge explicit and reflective for people. It also improves the creativity and leads to more sustainable solutions [8]. Thus, collaboration is an important driver for ideation and IT tools should provide appropriate possibilities.

However, there are a few POC try to make use of the innovative potential of patients, e.g. *gemeinsamselten.de* or *innovationbyyou.com*. The former online community focusses on the development of ideas in the context of rare diseases; in contrast, the latter has a more specialized focus and specializes in stoma and continence issues.

Against this backdrop, current literature looks particularly at how communication and collaboration on such platforms can be supported [9], [10], what motivates patients to contribute to POC [1], [11], [12] and whether the development of ideas in POC is accepted by stakeholders [13]. Our article contributes to this field by looking at the quality of ideas developed in POC, as well as whether patients are an adequate target group to develop healthcare related ideas. Thus, this article answers the research question: “How can existing POC be expanded in order to enable a structured, collaborative ideas development by patients?”

2 Research Methodology

As there is only little academic information systems research regarding the development of ideas in POC, the deduction of designing such concepts from theory is hardly possible. We therefore conducted our research as Action Research according to [14] (Fig. 1). Action Research is defined by [15] 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.” By iteratively designing a novel, socio-technical artefact in the form of a modular extension of POC called *Ideenschmiede*, we were able to improve the artefact, and from the resulting interaction with the community, we learned continuously.

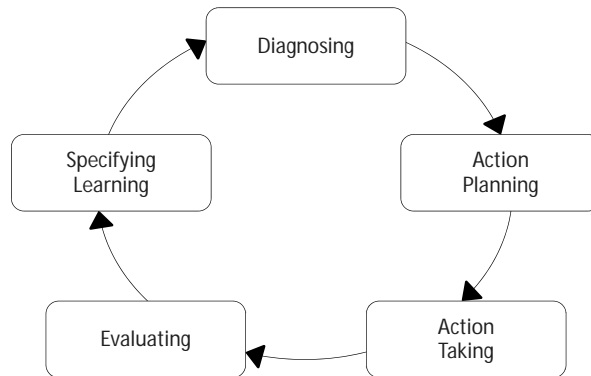


Fig. 1. Action Research Cycle [14]

The structure of the rest of this paper follows the process of this approach. Within the phase “Diagnosing,” we describe the problems of an online community consisting of patients that suffer from the disease Amyotrophic Lateral Sclerosis (ALS). The phase “Action Planning” presents our developed artefact Ideenschmiede. The section, “Action Taking,” describes how we piloted our artefact and how we integrated it into the ALS community, that is, how we made the artefact available for the community. We then evaluate our artefact by measuring the quality of the created ideas and analysing the recorded website statistics. A discussion of the gained results and conclusions of our research completes this article.

3 Diagnosing

The object of investigation is the community around the ALS forum of the DGM e.V. (short for „Deutsche Gesellschaft für Muskelkranke“; in English “German Association for Muscular Dystrophy”). To do this, we cooperated with the DGM. As part of their service offerings, the DGM supports, amongst other people, those who suffer from Amyotrophic Lateral Sclerosis (ALS).

3.1 Background Information about ALS

ALS is a degenerative disease of the central nervous system, on average leading to three years before death occurs [16]. ALS is a rare neurological disease, for which the reasons for this disease are still unknown and for which there is no known cure available [16]. With this disease, functional disturbances of the nerves emerges, which then causes deficiency of the musculature. The patients thus suffer mostly from chewing and swallowing difficulties [16]. Although there are no official numbers, it is generally assumed that 6,000 people in Germany suffer from ALS [17].

3.2 Problem Description of the ALS Community

As a part of their website, the DGM runs an Internet forum about ALS. In this forum, people suffering from ALS or those who know others having ALS can communicate with each other. They use the forum to exchange information about ALS and to discuss personal problems associated with ALS, thus resulting in a wide range of topics addressing ALS.

Additionally, the users share ALS-related ideas, which focus on the improvement of the everyday life of ALS patients and their relatives in order to guarantee a maximum of a self-determined life. Mostly, they share information about (self-developed) tools and about how they can adapt these tools to meet the specific requirements of ALS patients. 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. That is why such ideas often receive no consideration. To be more specific on this issue, the next section analyses in greater detail the structure of a typical Internet forum – as is the case for the ALS forum.

The major structural element of forums is the so-called thread. Users who are registered are entitled 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 sorting of the posts is according to the publishing date. Thereby, the oldest post is the first one. If a thread consists of a big number of user posts, these posts are spread over several sites within this specific thread. This is why users do not recognize new (eventually) important posts, as these posts are not visible at the front page of the thread. This effect is also observable in the field of the search engine optimization and search engine marketing. Nearly 87% of all users of Google Search just look at the first page of Google's hit list [18], ignoring the following pages of the hit list. This effect is not beneficial for ideation, as the ideas development often happens iteratively and takes place through intensive discussions.

The users of the ALS forum are aware of these limitations, which is why they tried to develop an appropriate structure in the forum. For instance, they created a specific thread on useful medical tools. They achieved a first categorization of ideas, but the large distribution of ideas over several pages still exists. Tracking regarding the development of the ideas is consequently very time consuming. Feedback targeted at specific ideas within the thread is also difficult to get. In sum, there is a lack of structural and collaborative capabilities. To address this lack, our developed concept provides measures for instance a wiki function allowing collaboration on one specific idea.

4 Action Planning

Our solution idea is a modular extension of the ALS forum called Ideenschmiede. The Ideenschmiede is not a platform itself that needs a new community; rather it is an additional tool for the existing community of the ALS forum. Hence, the Ideen-

schmiede draws on the ALS user database and technically is not integrated into the ALS forum.

Regarding the structural aspects of the Ideenschmiede, we applied the core functionalities (publishing of ideas, discussion and evaluation of ideas) to enable an ideation process. These are functionalities found in successful ideas communities such as "Tchibo Ideas" or "My Starbucks Ideas." To represent ideas, we used in a first prototype the following elements derived from an ideas ontology developed by [19]: (1) title, (2) abstract, (3) description, (4) author, (5) tags, and (6) comments.

In order to allow a collaborative ideas development, we added the elements "date" and "version number." These elements are necessary to create instances of the same idea and to track the current development status of an idea [19]. Hence, the users of the Ideenschmiede are able to change an idea directly – for instance, the elements "description" or "title". This functionality is analogue to a Wiki, where other users can change articles directly in the corresponding text field. Apart from that, we added the element "rating" [19] to allow ALS patients the evaluation of the developed ideas. Due to the iterative development of the Ideenschmiede, we tested this first prototype at a muscle discussion group (20 participants). This workshop revealed that the ALS patients did not differ between the elements "abstract" and "description" of a particular idea. Nearly all of the ALS patients put their ideas in the element "abstract," assuming that they had to add the same text in the element "description" again. To solve this issue, we deleted the "abstract". Afterwards, we tested a second prototype with the final ideas representation (Fig. 2) at a meeting of an ALS discussion group (30 participants) and improved after that some minor issues, mainly in terms of usability.

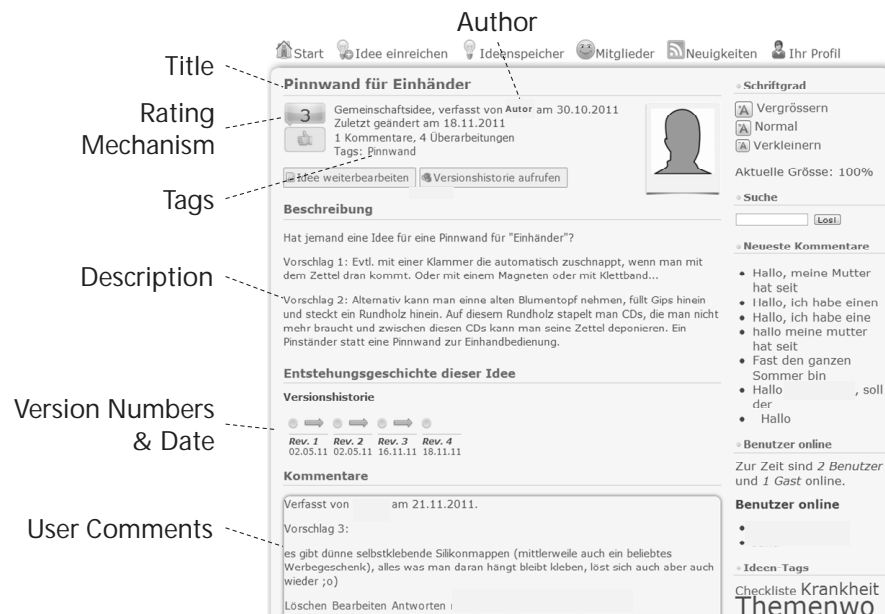


Fig. 2. Final ideas representation on Ideenschmiede

5 Action Taking

On 21th November 2011, we launched the Ideenschmiede (Fig. 3). We actively informed the ALS community of the launch of the Ideenschmiede by using press releases, an article in a regional newspaper and postings in the ALS forum of the DGM. We stimulated the ALS community by introducing a so-called “theme week” entitled: “How can I tell my relatives that I have ALS?”. The ALS community was encouraged to develop ideas regarding this topic collaboratively by using the Ideenschmiede. With the launch of the Ideenschmiede, we actively intervened in our object of research - a key characteristic of Action Research [20].

Furthermore, we welcomed every newly registered user of the Ideenschmiede by sending a personalized message. In this message, we informed users of the intention of the Ideenschmiede, about the current theme week, who was responsible for the Ideenschmiede, etc. We also invited them to evaluate published ideas and to send us feedback, along with their questions regarding the Ideenschmiede. With this feedback, we hoped to optimize our developed concept. Thus, we collaborated with ALS patients, which, according to [20], is another characteristic of Action Research.

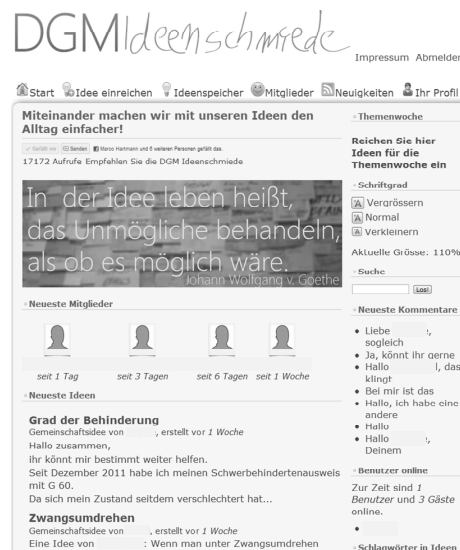


Fig. 3. The developed module Ideenschmiede (www.dgmideenschmiede.de)

6 Evaluating

We evaluated our concept according to the Action Research Cycle. In order to analyse the functioning of our artefact, we conducted a two-step evaluation. The first step was the analysis of descriptive data in terms of the general usage of the module Ideenschmiede, and the second step comprised an evaluation of the ideas quality. This

approach not only indicates the user acceptance of the artefact, but also evaluates whether patients can be innovators, as consumers can be.

6.1 Analysis of General Website Statistics

Between the launch of the Ideenschmiede on 21th November 2011 and 1st August 2012, 194 users registered and developed overall 56 ideas around the topic “ALS.” 45 of these ideas are collaboration ideas that other registered users can develop further. In contrast, there are 11 so-called individual ideas that are not changeable by other users. The users of the Ideenschmiede reviewed 14 of the 45 ideas at least once, bringing the share of reviewed ideas to 31.1%. The users also generated 105 comments and rated 30 ideas. We can thus conclude that these collaboration ideas fulfil the requirements of the collaboration principle. To be more precise, we postulate that all participants of a collaboratively developed idea have a shared understanding regarding the underlying problem and that there was a minimum of communication amongst the involved collaborators [21].

Next, we performed a first analysis regarding the website usage over the same period. For this, we used the analysing tool Piwik (version 1.7). A first analysis of the recorded data shows that the Ideenschmiede had 5,146 unique visits from registered users, with 4,079 visits from registered users in Germany. 696 identified visits were from users in Switzerland, while 270 visits from the USA; 101 visitors came from other countries. Every visitor executed about 5.8 actions. The average time spent on the Ideenschmiede was about 6 minutes and 33 seconds per user. The reason for this relatively high residence time is probably that the users are mostly highly limited in their motor capability caused by the ALS. For this reason, in comparison to healthy users, they can use their computers relatively slowly and consequently need more time to get an overview of the current content or to publish their content. Furthermore, the majority of the registered users visited the Ideenschmiede on a regular basis, as 3,315 of 5,146 visits were returning visitors. These users are also mostly those who regularly publish new ideas and develop existing ideas further or comment on ideas.

6.2 Measuring Ideas Quality

To assess the quality of the published ideas, we applied the Consensual Assessment Technique (CAT) by [22]. CAT is an adequate method to assess ideas quality [23]. In the following section, we present the measurement of the idea quality, considering the applied scale as well as the evaluation process itself.

Evaluation of the ideas quality based on CAT. Idea quality is a complex construct. Hence, the literature provides various metrics consisting of different dimensions for assessing the quality of creative ideas [24]. [23] used eight dimensions to measure ideas qualities: (1) novelty, (2) originality, (3) paradigm relatedness, (4) technical feasibility, (5) economic feasibility, (6) acceptability, (7) effectiveness and (8) elaboration.

A key criterion when evaluating ideas is **novelty**. An idea is described most novel if – from the perspective of its contemplator – it is rare and nobody has previously expressed it [25]. We adapted novelty in our scale. **Originality** is another dimension discussed in evaluating ideas. An original idea is defined consistently as an idea that has the characteristic of being inconvenient, visionary and surprising [26]. We integrated this criterion in our scale. **Paradigm relatedness** refers to an idea’s transformational character, and describes the degree to which an idea helps to overcome established structures [26-28]. We did not apply paradigm relatedness in our scale, as this criterion does not fit in the context of ALS patients. People who suffer from ALS are very open-minded and actively watch for solutions to simplify their everyday life. **Technical feasibility** refers to the question of whether or not the underlying idea is transformable into an applicable solution, concerning the capabilities of ALS patients [26], [29-31]. Thus, we integrated this criterion in our scale. **Economic feasibility** concerns the question of whether or not an underlying idea is realizable as a product within an acceptable budget [25],[32-35]. As ALS is a very cost intensive disease, this aspect is an element of our scale as well. **Acceptability** expresses the degree to which others accept an idea regarding the respective social, legal or political aspects [36], [26]. We adopted acceptability in terms of the acceptance of the developed idea by ALS patients. **Effectiveness** describes the degree to which an idea will solve a problem [30], [35]. **Elaboration** can be seen as the extent to which an idea is complete, detailed and well understandable [25], [26]. We adapted effectiveness and elaboration to our scale. In the next step, we operationalized each of the idea qualities’ distinct dimensions by one item (Table 1.)

Table 1. Scale for ideas evaluation (based on [23])

Dimension	Corresponding item
Novelty	The idea delivers an unprecedented new approach in terms of the respective underlying problem.
Originality	The idea is unusual, fanciful, original and surprising.
Technical feasibility	The idea is - from the technical perspective (within the available know-how and individual conditions) - easy to implement for ALS affected persons.
Economic feasibility	The idea is - from the economics perspective (within an acceptable budget) - easy to implement for ALS affected persons.
Acceptability	The idea has the potential to meet the goodwill of the majority of ALS affected persons.
Effectiveness	The idea solves the underlying problem in a simple manner.
Elaboration	The idea is complete and mature.

Assessing the idea quality. We randomly selected 24 ideas generated by users of Ideenschmiede. By using the CAT method, a jury - consisting of experts in the domain of ALS - evaluated these 24 ideas. In our case, the jury consisted of three referees. The first referee was working for the DGM e.V., while the second was working for a hospital specialized in ALS. The third referee was chairperson of a self-help association for muscle diseases in general and for ALS in particular. For the evaluation, we pasted each idea description into separate evaluation forms containing the scales for the idea evaluation. Hence, each referee received 24 evaluation forms electronically in randomized order. All judges were assigned to rate the ideas with the seven different items on a rating scale ranging from 0 (lowest) to 4 (highest). Each member of the jury evaluated the ideas independently from any others.

According to Amabile [22], the reliability of a scale that is used in the scope of Amabile's CAT is good if all judges of the jury evaluate the ideas concerning each dimension almost equally. That means that ratings on each dimensions should be analysed for inter-rater reliability [22]. We checked the inter-rater reliability for our case by calculating Intra-Class-Correlation (ICC) coefficients (Tabelle 2). Following [37], we used the interpretation scale: poor to fair (<0.4), moderate (0.41-0.60), substantial (0.61-0.80), almost perfect (0.81-1). In our case, most ICC coefficients are moderate. The ICC coefficient for "originality" is substantial (0.637) and "effectiveness" is close to substantial. As most of the coefficients tend towards 0.60 and as our research is explorative, we deem the reliability of our results to be acceptable [23]. These numbers confirm the construct validity, and thus we can assume that our idea measuring scale shows a sufficient degree of construct validity.

Table 2. ICC-Coefficients for each ideas dimension

Ideas dimension	ICC-Coefficient (two-factorial, random)
Novelty	0.546
Originality	0.637
Technical feasibility	0.529
Economic feasibility	0.515
Acceptability	0.545
Effectiveness	0.598
Elaboration	0.473

In order to express the degree of the quality for each of the 24 evaluated ideas, we constructed a quality index, reaching from 0 to 84. This index is calculated as follows: all of the seven applied evaluation dimensions can have a maximum value of 4. Each idea covering all evaluation dimensions can have a maximum index of $7 \cdot 4 = 28$ per referrer. As we have three referrers, the maximum index for every idea is $28 \cdot 3 = 84$. Accordingly, the minimum index is $7 \cdot 0 \cdot 3 = 0$. The evaluated ideas reached quality scores between 18 and 79 (Table 3). The average value is 50.83 and standard deviation is 13.637. The Kolmogorov-Smirnov test confirmed the normality of the distribution ($p=0.480$).

Table 3. Statistical values regarding the results of the ideas quality

Statistical values	
N	24
Average value	50.83
Standard deviation	13.637
Minimum	18
Maximum	79
Kolmogorov-Smirnov-Test	
Kolmogorov-Smirnov-Z	0.840
Asymptotic significance (bilateral) (p)	0.480

Figure 4 shows the quality indices for every evaluated idea, including the average value of 50.83. Compared to the maximum achievable 84 points per idea, 75% of the evaluated ideas are above the medium level of 42.

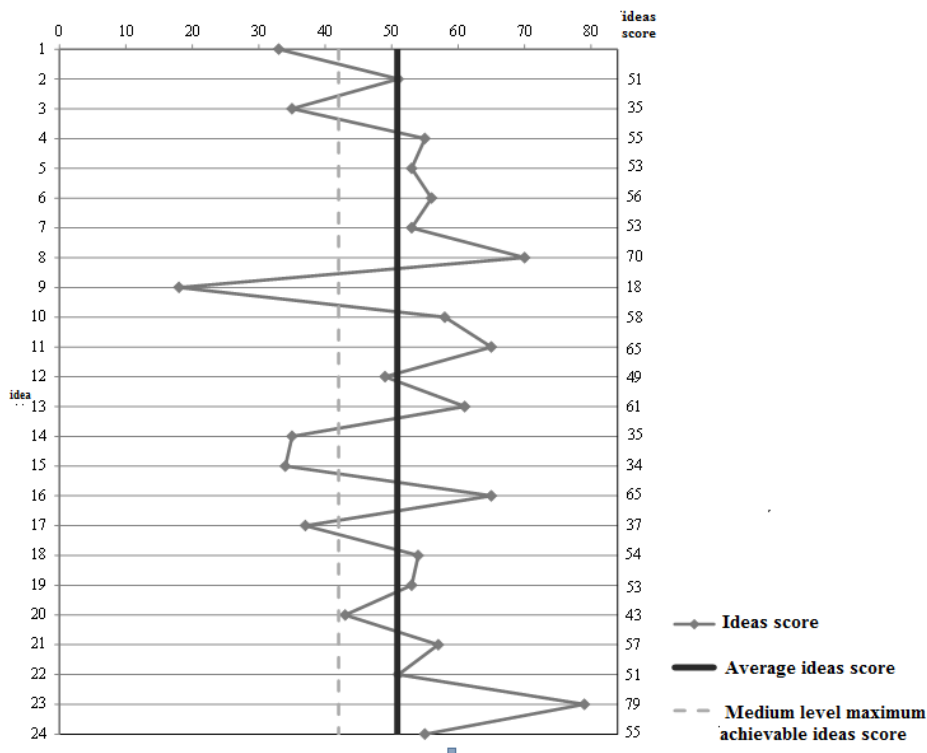


Fig. 4. Quality indices of the ideas developed on Ideenschmiede

In other empirical work such as [24] or [38], [39] mostly all ideas are of a medium level. In comparison to these studies, the ideas from the Ideenschmiede are of a higher quality. We assume this is as a result of the users' motivation to use Ideenschmiede.

Developing ideas for a commercial community provided by a company such as Starbucks, Tchibo, SAP, etc. means that the company is the addressee of the created idea. The customer has only an indirect benefit. In the case of the Ideenschmiede, the ALS patients developed ideas for other ALS affected persons and themselves. Hence, they can benefit directly, which may be a reason for our results. Nevertheless, the evaluation of these ideas is objective and we cannot currently state whether ALS patients apply these ideas in reality and if these ideas really help them.

By referring to our defined research question: “How can existing POC be expanded in order to enable a structured, collaborative ideas development by patients?” we can state that the modular extension of a POC through the Ideenschmiede is a possibility to support such an ideation process. Further, we can state that patients can generate ideas of at least medium quality.

7 Discussion and Conclusion

According to [14] specifying learning is the last step in Action Research Cycle. Indeed, it is a continuous process along the cycle and can contain three possible outcomes:

1. Reflected new knowledge gained by the organization
2. Learning for a new intervention, in the case of an unsuccessful change
3. Knowledge gained from the theoretical framework

Looking at the first point, we can say that the ALS patients collaborate and develop ideas, although the numbers regarding the user activities on the platform are not very good per se. We assume that one reason for these numbers is that the Ideenschmiede is not functional integrated in the DGM ALS forum due to technical restrictions. From an **organizations’** perspective this would be an important point to consider, when a module such as the Ideenschmiede shall be implemented in a community.

We could also demonstrate that patients have the potential to develop innovative ideas. As we have shown, this innovative ideas potential can be leveraged with the help of ideation platforms. Managers of a POC might lean on the insights of our research as other POC certainly suffer from the same class of problems that underlies our research.

In terms of the preparation of a **new intervention**, one should consider if another patients group with a larger user base would be more appropriate. This would lead to more user generated content in form of ideas or comments, which would in turn support creativity and thus collaboration.

Looking at our **theoretical framework** we can state, that the ideas ontology by [19] is a good instrument, to represent ideas on online platforms. The implemented elements are simple to use, but simultaneously deliver a structure, which allows the generation of ideas as well as the collaboration on ideas. However, this ontology should be adapted for the specific requirements of the target group. [19] derived their ontology elements by assuming an innovation manager has to choose the best idea from a large pool of ideas. Hence, an element such as “abstract” would be a useful

mechanism to gain a first overview about the single ideas. In our context, the advantage of a simplified ideas submission prevails. Furthermore, our empirically findings inductively provide feedback to the theoretical idea ontology by [19], which could lead to a more precise idea ontology. By doing so, we could contribute to theory by extending the body of knowledge.

Another point we can learn from our intervention is, that there is lack of collaboration tools that can be easy implemented and that can intuitively be used [40]. Our approach provides text-based collaboration analogue to a wiki, which is easy to use. In terms of a collaborative advancement of ideas, other tools (e.g. innovation toolkits) could be more appropriate. Nevertheless, we can state that there is collaboration among patients and that concepts for ideas development are transferable to health care.

However, our results are limited, as the obtained results originate from POC where members suffer from the deadly nerve disease, ALS. Hence, it would be useful to compare Ideenschmiede with ideas communities [41] in different environmental settings (such as ideas communities for customers or for open source developers) in terms of idea quality, collaboration processes, motivations, incentives, etc. Another promising approach would be a comparison with ideas communities having a user database with a different personal background in terms of diseases, personal experiences, medical knowledge, etc. It can be assumed that these users create ideas on a different quality level. Transferring our concept in these contexts could deliver further insights with respect to its effectiveness and efficiency.

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