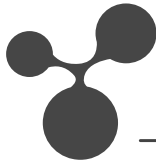


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C.4 IT-based Interaction Platforms to Foster Virtual Patient Communities

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1 Introduction: Challenges in health care

Populations of developed economies are ageing and those of developing economies are growing due to a significant demographic change (United Nations, 2002; 2009). Western countries such as Germany, the U.S., and France witness diminishing birth rates and an increasing life expectancy. As a consequence, these countries are exposed to growing health care costs at an unsustainable rate, one which is roughly twice the rate of economic growth (OECD, 2010). This development calls for rebalancing efficiency and health care costs while improving quality of care for patients.

While other big industries than health care have adopted the advantages of the information technology (IT) age since the 1980s (Schepers, Schnell, & Vroom, 1999; Von Hippel, 1988), the health care sector has been quite hesitating to do similarly. Now, the influence of technological advance on health care is likely to further increase (Randeree, 2009). One of the recent developments, which is termed *health 2.0*, has been the use of Internet or web-based technology in health care (Oh, Rizo, Enkin, & Jadad, 2005; Van De Belt, Engelen, Berben, & Schoonhoven, 2010). Recent studies give evidence that the number of Internet users worldwide, who go online for health-related purposes, is growing significantly (Kummervold et al., 2008). Over the past few years, many virtual communities for patients have arisen to give information about disorders and facilitate networking with like-minded sufferers. The web sites help patients to better understand and manage one's individual health status. Some reports herald that it is a powerful and disruptive means to changing current patients' role and medical practice. Some research has been done to better understand how to systematically develop and operate virtual communities in health care (e.g., Leimeister & Kremer, 2006).

The aim of the study at hand is to gain insight into the current developments in the domain of health 2.0 and to examine IT-based communities on the Internet that foster the emergence of patient interaction. At first, we present the background of web 2.0 in health care (cf. chapter 2). Subsequently, we present four exemplary case studies (cf. chapter 3), followed by a discussion on possible dimensions of how to classify health 2.0 platforms (cf. chapter 4). Concluding remarks on limitations and future research closes the paper.

2 Setting the scene: Web 2.0 in health care

The term *web 2.0* was initially introduced following the O'Reilly Media Web 2.0 conference in 2004. It summarizes the changes that had happened on the Internet and the way how its users deal with it. A set of economic, social, and technological trends led to the next generation Internet which is characterized by user participation, openness, and network effects (Musser & O'Reilly, 2007; O'Reilly, 2005). Compared to Web 1.0, the so-called first generation of the Internet, the difference of Web 2.0 is foremost about user interaction. While Web 1.0 was mainly about unidirectional information retrieval, users can create and add information and content to the Web. For that reason the amount of user-generated content has increased enormously (OECD, 2007). Since then online communities, in which users can participate and share content, have become very popular.

This recent trend has also shown impact on health care related online offers which is then described as *health 2.0* or *medicine 2.0* (Eysenbach, 2008; Hughes, Joshi, & Wareham, 2008; Van De Belt, Engelen, Berben, & Schoonhoven, 2010). Both terms cannot be separated distinctly, and are sometimes used synonymously. They are subsumed in the broader term *e-health* which was first introduced in 2000 in the context of *telemedicine* (Mitchell, 2000). Van de Belt et al. (2010) have undertaken a literature review in health 2.0 and medicine 2.0. They conclude by finding seven leading themes within all definitions:

- 1) Increased participation or empowerment of patients or consumers of health care,
- 2) Web 2.0 as the underlying technology for communication and information sharing,
- 3) Apart from patients only, increased participation or empowerment of health professionals or other stakeholders, e.g. payers, providers, researchers,
- 4) Emergence of online communities and social networking in health 2.0,
- 5) Positive impact or change on the health care system in terms of higher quality and efficiency in health care,
- 6) Improving collaboration between patients and health professionals, and
- 7) Stronger focus on health information and content, one that is patient-driven or user-generated.

At this point, health 2.0 platforms seem promising for two reasons. Firstly, the web 2.0 provides features that help to give users an active voice on the Internet. Compared to the first generation of the Internet, web 2.0 is foremost characterized by user participation, openness, and network effects (Musser & O'Reilly, 2007). Accordingly, health 2.0 platforms can leverage patients' knowledge base through user interaction. It is particularly important to obtain both need information and solution information from the patient as both types of information are crucial to value-creation in new product and service development (Reichwald & Piller, 2009; Thomke, 2003; Von

Hippel, 1994). Traditionally solution information was provided by the manufacturer of a product, but now user interaction in health 2.0 can help to transfer this valuable knowledge from the patients' minds to a public space like online communities from where it can be harvested by manufacturers.

Secondly, patients obtain easier access to health-related information and thereby are able to gain better understanding of their health status. In peer-led patient communities, not only provide users each other with knowledge and support, they also enable one another to comprehend the necessary medical information and science in the context of the respective disorder (Frost & Massagli, 2008; Hoch & Ferguson, 2005). Such communities are characterized by a high degree of interaction between users, and reciprocal exchange of information.

Several studies report that the role of the consumer is transforming into a more informed, engaged, and empowered one (Akesson, Saveman, & Nilsson, 2007; Bos, Marsh, Carroll, Gupta, & Rees, 2008; Füller, Mühlbacher, Matzler, & Jawecki, 2009). Also, health 2.0 influences the roles of health professionals and researchers and how they interact with empowered patients (Eysenbach, 2008; Wald, Dube, & Anthony, 2007). The emergence of these interactive capabilities enable virtual health communities to be an effective source of jointly constructed and shared knowledge through participation of patients, caregivers, health professionals, and researchers.

3 Exemplary health 2.0 cases

As practice and research in the field of health 2.0 is still recent, we chose an exploratory approach to study contemporary real-world practices on health platforms. In the following we present four descriptive case studies, which we consider as promising practices. They differ by the different implementation levels of virtual communities.

3.1 NetDoktor

One of the first health 2.0 platforms in Germany was *NetDoktor*¹ – a portal that already went online in 1999. Meanwhile the platform has developed into one of the best-known and most visited sites in Germany (Weller, 2009). It addresses a broad audience of both the well and the sick.

NetDoktor predominantly serves as a portal providing independent and comprehensive information around health and medicine. Online encyclopedia provide hard facts and physician editors publish articles on general health advice ranging from alcohol abuse over menstruation to vaccinations. Dedicated theme pages are available for specific diseases such as asthma, cancer, or swine flu. The business model mainly bases on advertising revenue and content licensing, i.e. commercialization of content to interested partners. Hence, the quality of the editorial contributions is of key importance.

¹ <http://www.netdoktor.de>

Moreover, since 2009, *NetDoktor* has added discussion boards where patients can post questions and reply to other's questions across a variety of health-related topics. This function enables users and patients to interact and learn within topic-centered communities. As a service feature, the platform offers to its users the search for doctors, pharmacy emergency service, and external self-help groups.

3.2 Imedo

*Imedo*² is a health 2.0 platform that puts a stronger focus on development of patient communities than the previous example. The portal, that was founded in 2007 and counts approximately 80,000 registered users, addresses a broad audience across various health topics ranging from general health to chronic disorders. Its users are health seekers, patients, doctors, or members of self-help groups.

The central function of *Imedo* is its community. The typical element is discussion boards that help users to exchange knowledge and expertise on their health problems. Apart from that, *Imedo* has implemented a number of community features that distinguishes it. Outside of the discussion boards, users are able to raise individual questions to find quick answers and straight-forward solutions through other experienced users. Furthermore, users can formulate individual health goals and a personal buddy in the community, called "motivator", supports and checks on reaching the goal. In each personal profile, users have the option to give information about their health-related interests, currently used medicines, and applied therapies. This helps to more easily find like-minded users and thereby promotes the value of the community network.

In order to combine online and offline world, *Imedo* operates a search function for patients to find medical specialists within Germany. Users can also write reviews on a specific doctor, give ratings, and share this information with the community. Apart from this, *Imedo* offers a dictionary of medical terms and a news section that complement the discussion boards with hard facts.

3.3 Gemeinsam für die Seltenen

On the platform *GemeinsamSelten*³, users can initiate and participate in finding ideas and solutions that help sufferers of rare diseases. The site, which has been launched in March 2011 and addresses a German-speaking community, accommodates three main functional components: an innovation initiative based on a series of contest-like challenges, a social network, and a marketplace for exchanging problems and ideas. The platform strives to collect problems of rare disease patients and, thereby, increase public awareness. The aim of the site is to develop innovative solutions for the patients' reported problems through innovation contests. Across the great variety of illnesses, patients and their families are often confronted with similar types of problems. The

2 <http://www.imedo.de>

3 <http://www.gemeinsamselten.de>

site targets people who know about the daily troubles of rare disease patients – may it be the patient himself or persons concerned. These people might have thought about tricky problems, possible solutions and even practical implementations. However, in order to become a participating member, interested people do not have to possess experience on rare conditions. The intention of the site is to bring people from diverse backgrounds together – if it is caregivers, health workers, physicians, nurses (i.e. core inside innovators); family members, friends, fellow patients (i.e. peripheral inside innovators); or researchers, engineers, product managers, civil servants (i.e. outside innovators).

The research group behind the platform organizes so-called *challenges* in which participants can compete for the best ideas. During a challenge, which lasts approximately three months, participants can present unsolved problems, submit solution proposals, and collectively work on refining ideas and concepts. At this point, the social community features of the site enable members to create a personal profile, connect to others, discuss ideas, and comment on others' contributions. Proposals for solutions on *GemeinsamSelten* can cover descriptions on technical aids and products, medical and caregiving services, medical-technical services, or housekeeping and social services.

After the closing date of each challenge, a jury of experts assesses the most innovative concepts. The multi-disciplinary jury consists of researchers and practitioners from clinical as well as commercial organizations. The jury members evaluate each solution proposal along a predefined set of criteria such as novelty, usefulness, feasibility, market potential, and degree of elaboration. Not only do final winners of the contest collect prizes, but they are also supported in innovation workshops to develop concepts for prototypes.

In brief, the platform has three distinctive features; it (i) organizes a series of innovation contest-like challenges to find solutions for improving the quality of life of rare disease patients, (ii) collects patient's problems and needs in a central place, and (iii) creates a community with people from diverse backgrounds to promote knowledge exchange and collaborate on innovative concepts.

3.4 PatientsLikeMe

The platform *PatientsLikeMe.com*⁴ is a health information system that looks at first glance similar to patient chat rooms and support groups. The site, which has been operating since 2006, is specifically designed for patients to meet and discuss with other patients about their ailments. With a clear focus on patients facing life-changing and rare illnesses, the ~97,000 registered patients (as of March 2011), mainly from the U.S. and the U.K., are organized in disease-based communities, such as amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), fibromyalgia, acquired immune

4 <http://www.patientslikeme.com>

deficiency syndrome (AIDS), depression and anxiety. Compared to other platforms in the health 2.0 space, *PatientsLikeMe* has one of the most innovative approaches. In this system, patients give detailed record about their health information and, then, make it public to the community. The record contains a combination of structured and unstructured data about symptoms, severity, progress, medication and their side effects. Health data is neatly represented using standardized metrics and clear graphical displays. Once shared with other patients, they can enter active dialogue via the web platform and learn from collective knowledge and experience.

Another outstanding characteristic of *PatientsLikeMe* is the dedicated openness philosophy within the community – in addition to their privacy policy towards non-members. For most online users, protection of private and personal data is an imperative that platform operators must adhere to. For patients with incurable and life-changing diseases who are looking for ways to prolonging their life, the case might be different. The makers of the site assume that open collaboration on a large scale with real-world data enables change, and possibly new treatments.

Apart from patients, there is collaboration with several nonprofit groups as well as pharmaceutical companies. It is an essential part of the business model. *PatientsLikeMe* is very clear in stating that aggregated anonymous data is sold to drug, device, and insurance companies – all with the consent of its members. For example, *Novartis* and *Avanir*, both research-based pharmaceutical organizations, are partnering with the site to recruit participants for clinical studies. These firms can publish online pre-screeners on the site that help to select patients who are eligible for e.g. a clinical trial to test drugs. In the case of *Novartis*, it is reported that the site helped to speed an MS trial by several months (Arnst, 2008).

In brief, *PatientsLikeMe* offers (i) graphically enhanced personal health record for rare disease patients, (ii) open sharing of personal health data in social network, and (iii) matchmaking between patients and researchers.

4 Discussion

In the previous sections we have seen four examples of community interaction happening on health 2.0 platforms. Going forward, we discuss potential dimensions for classification. In the above discussed examples, the platform user finds himself/herself linking-up with a variety of stakeholders resulting in a distinct degree of interaction between community members. Hence, we assume that the value of the patient community largely depends on two major dimensions which are discussed in the following.

Firstly, from the perspective of a patient, there are numerous relationships to problem solvers who can deal with the patient's health problems. In the first place, it is the relationship to a dedicated general practitioner who typically has the best overview of the patient's health status. In the course of medical treatment, the GP might send the

patient to medical specialists for further examination. In addition to the GP, the patient could consult other medical experts on a one-to-one basis, ranging from technical encyclopedia to health counselors from industry partners. Due to its functional focus on serving as an information portal, *NetDoktor* is a good example which links its users up with medical experts in form of physician editors.

As a consequence of health 2.0, the traditional one-to-one relationship between doctor and patient is supplemented by a number of new relationships with like-minded people. Here, one major group consists of fellow patients who suffer from a similar disease pattern and also their caregivers and family relatives who suffer indirectly. They all have acquired relevant experience and knowledge in the same field. Fellow sufferers are less familiar with the patient's detailed situation than the supervising GP but still can share relevant experience. Here, the platform *Imedo* demonstrates how users can learn from community members' experience to solve individual problems. Other stakeholders who do not directly share disease experience with the patient make up a third group. They can contribute specific technical knowledge in order to solve, or at least facilitate dealing with, the patient's health problem. These could be, e.g., industry partners like medical device manufacturers or service businesses specialized on a particular aspect of medical care. At this point, especially *GemeinsamSelten* and *PatientsLikeMe* successfully connect patients with medical experts, other patients, and further stakeholders.

From the above we propose that the first dimension is about patient-related interaction groups consisting of three clusters: (i) medical expert-to-patient relationships, (ii) patient-to-patient relationships, and (iii) other stakeholder-to-patient relationships. Secondly, health 2.0 can be classified along the degree of community interaction. On the one hand, there are online sites which do not, or at least not to a recognizable extent, have a dedicated interaction focus. These are mostly sites characterized by unilateral information dissemination, e.g., *NetDoktor*. On the other hand, online platforms with well-developed communities, such as *Imedo*, *GemeinsamSelten* and *PatientsLikeMe*, certainly have a higher degree of interaction. Different measures could be applied here: number of discussion posts, posts per community member, share of active members, etc. Hence, we propose a second dimension to classify health 2.0 platforms: it is about the degree of interaction along a simple scale of low-medium-high.

Another important discussion point is about risks in health 2.0. Of course, a fateful illness will not be cured by surfing on the web. The personal relationship between a patient and his doctor remains paramount. But patient-driven healthcare is a trend that takes up and people are going online to get more knowledgeable about their illness. It is a question if users who publish personal health information online fully understand the risks of harm and misuse and if platform operators are successful in enforcing privacy – on the one hand to create trust towards users, on the other hand to comply

with local law. Confidentiality needs to be closely monitored if patient data, even in anonymized and aggregated form, is sold to companies. Furthermore, user-generated data is still poorly controlled and factors such as over-reporting of symptoms, data quality, and selection bias might influence results.

5 Conclusion

Patient communities in the context of health 2.0 are still a developing topic. In a first step, we portrayed four examples in this field. Specifically we looked at the different implementation levels of virtual patient communities. With this at hand, we discussed two major dimensions that can help to classify health 2.0 platforms. One is about user's interactions with other user groups like medical experts, other patients, and industry or nonprofit partner. Another is about the degree of interaction triggered by the user community, which runs from low degree of interaction with predominant focus on information only to high degree of interaction between community members. Results of this study have to be seen in the light of its limitations which also opens a number of research questions.

Firstly, the classification approach is conceptual only at this point in time. On the one hand, we only discussed two dimensions while other relevant scales, e.g., user segmentation or innovation focus, fall off. On the other hand, it lacks empirical foundation which is needed to substantiate it over time.

Secondly, it is easy to start a debate over blurring lines between clusters of a dimension. For example, the 'degree of interaction' is based on an ordinal scale only and yet remains open to be measured on a metric scale. Nevertheless, we believe the two dimensions serve a functional purpose: they assist in quickly differentiating the wealth of health-related sites from a community-research perspective.

For future research, findings from studies on interaction in online and offline communities need to be connected to the context of patients and other stakeholders involved in health 2.0. Beyond that, a thorough understanding of interaction and collaboration between all involved parties is required in order to study the emergence of innovation on health 2.0 platforms.

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