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The Role of Community Governance and Interaction Quality in Patient Organizations for Rare Chronic Diseases

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Abstract: An extensive body of literature indicates the growing influence of virtual communities on various aspects of people's life – from spending their free time, engaging in social interaction, to working. In recent years, companies engage in virtual and non-virtual interaction with their customers as part of their open innovation strategies. In doing so, they intent exchange information on products and development of innovative ideas. However, this kind of collaboration is not yet fully embraced by companies and still poses some organizational and individual challenges to companies. Especially in non-software industries as the health care sector of rare and chronic diseases where people are emotionally highly involved while bearing a great expertise, collaboration potential is not yet fully leveraged. This contribution explores two concepts drawn from current knowledge on virtual communities to be mainly responsible for a successful collaboration, namely the community governance as relevant organizational dimension and the interaction quality as paramount construct of collaboration. By reporting on preliminary results (due in October 2011) from a German-based study of anticipated 51 patient organizations of rare and chronic diseases, we aim to discover how patient organizations govern themselves, how interaction is facilitated among members and what performance regarding innovative ideas can be expected. This will lead to advice for companies as how to design their collaboration with patient organizations.

1

INFORMATIK 2011 - Informatik schafft Communities
41. Jahrestagung der Gesellschaft für Informatik , 4.-7.10.2011, Berlin

www.informatik2011.de

1 Introduction

Virtual communities (hereafter VC) affect the social interaction of people and shape different areas of their life, like working and spending free time [LA09]. Furthermore, they help their members to start new friendships, learn, form opinions, and exchange information on products and services [BD02]. Especially in health care, VCs like www.patientslikeme.com are gaining more and more momentum as information on health-related topics can be easily made accessible. At the same time, individual prevention is getting more important than ever due to extensive reforms and budget cuts in the public health sector in recent years.

In the specific case of rare and chronic diseases a large percentage of diseases cannot even be addressed within the regular health care system. Not only is the information often decentralized but patients are also often locally dispersed. Thus, more and more patients are actively involved in patient organizations and use the Internet in order to share experiences, discuss trends and treatments as well as to provide support [FR09, EP04]. Over the last years, these communities have become a major factor in the health care system. Besides providing passive support they have also started to actively influence policy makers and other stakeholders and act as innovation drivers for new treatments.

Although there have been some studies on the medical and psychological effects of patient organizations (hereafter PO) [FR09, EP04], we do not know much about their organizational structure and innovative activities. At the same time, research in the field of user and open source communities has over the last years extensively examined role settings, functions, hierarchies as well as communication patterns of VCs [see SH06, HE07, DL06] and has proven their economic impact. Consequently, our research aims at bridging the gap between research on VCs as a phenomenon of internet-based interaction and research on POs with organizational considerations, in order to get a better understanding on how POs leverage innovative potential. Our research is guided by the following questions:

a) What factors constitute a high quality of interaction among community members (horizontal) and members and executives (vertical)?

b) How do POs organize themselves in order to achieve their self-set goals (e.g. improve their members quality of life, information dispersion and raising awareness for the disease, etc.)?

INFORMATIK 2011 - Informatik schafft Communities
41. Jahrestagung der Gesellschaft für Informatik , 4.-7.10.2011, Berlin

www.informatik2011.de

To cover the research questions, a corresponding framework is derived from theory and will be tested in an empirical study. Among the central focuses of our analysis will be aspects such as patient participation, mutual support, coordination, and culture of the organizations. Additionally, we will look at the innovative activities and output of their members and link them with personal and organizational aspects. Furthermore, we will examine the interplay of the provision of different communication functionalities on individual innovative behaviour as well as the effect of formal and informal self-organization on the interaction and subsequent individual innovative behaviour. Results are expected to give a comprehensive illustration of Pos' organizational characteristics, interaction patterns, knowledge generation and dispersion. Results might consecutively allow us to draw conclusions as to how potential third parties (e.g. medical engineering companies) can engage in a fruitful collaboration and leverage the innovative potential of POs.

In the next section, we start with a definition of VCs in the context of patient organizations, followed by the development of a comprehensive research model on interaction quality. Subsequently, scale development, sample selection, and data collection are described. Finally, we discuss implications for further research.

2 Virtual Communities in the Context of Patient Organizations

In this section, we turn to define the research object and deduct its main aspects. Starting with the term VC as dominant phenomenon we aim at taking it into the context of patient organizations.

Due to the increasing popularity of virtual communities and in the course of using the term virtual community to describe almost every virtual interaction, the term itself became a buzz-word [PR00, LA06, LS06]. Furthermore, there are a substantial number of synonyms that describe the same effect [e.g. TW06, WL08]. Additionally, the concept of community roots in various academic disciplines, such as information sciences or sociology. These circumstances make it difficult to determine what is exactly meant when applying the term virtual community.

The many contributions made over the years emphasized a number of aspects and extended the definition with respect to specific context. If, however, the reason of the underlying collaboration is not exactly specified, benefits and learning can only be specified generally. In accordance with West and Lakhani [WL08] we advocate developing a definition "to explicitly articulate the theoretical and phenomenological boundaries of [the] use of the term" (p.224) to shed light on the various dimensions and how these can be adjusted to realize all the potential involved. Thus, we will shortly introduce the main concepts defining VCs, setting them into context of virtual POs.

3

2.1 Virtual Communities

Rheingold [RH93] provided the first and seminal definition of VCs building on his experiences with the WELL[1] community: "Virtual communities are social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyber-space" (p. 5). From a synopsis of over 30 definitions of VCs for innovation (for further information see [SH10]) VCs tend to be a very emotional matter despite the predominant aspect of virtuality [JM03] and the social limitations of Internet-based communication technology [MM08]. VCs develop a strong cohesion among members, proving a shared culture that states the ground for emotional fellowship [RH93], bound by the purpose of the community [PR00], [RS01]. From this, relationships can be built among members, providing emotional and mutual support [FJ07, PR00] individually and regarding the goals of the VC by means of interaction [FJ07, RS01]. Engagement is acknowledged by peers [WG01] and the concept of reciprocity [SH06] is applied. VCs can depict different operator designs, but we will focus on VCs established by private persons [WM08, SD07].

2.2 Patient organizations

In our specific setting we focus on patient organizations of rare and chronic diseases. Members of POs patient organizations can be seen as experts on their own behalf, as they know best about their problems and needs [BO04]. POs are built on the principle of active involvement, participation and activity of its members [MA99]. They are mainly characterized by pursuing three goals: information exchange among members, emotional support, and improvement of quality of life [SG00].

For this contribution, we lean towards the definition of the National Contact and Information Service (NAKOS – Nationale Kontakt und Informationsstelle) and understand virtual patient organizations as a member-initiated, internet-based exchange of a group of people that share a common problem or are affected by the same disease. Together, they pursue the goal to share experiences and exchange relevant information. In doing so, they rely on synchronous and asynchronous communication channels. Their exchange is independent from space and time, as patients are often locally dispersed (nationally and internationally). The groups are characterized by low access barriers in order to invite all potential members to participate regardless from their specific impairment. The organizations are established and run by private persons, only rarely supported by professionals and pursue no commercial interests.

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[1] The WELL is short for Whole Earth 'Lectronic Link, a community that was bound by shared interest of its members covering a vast amount of topics from everyday life. In his book, Rheingold describes his experiences and learning from his engagement with the WELL community.

4

Thus, the unit of analysis of this contribution are POs that additionally engage in internet-based virtual interaction as means of connecting their members, addressing the public and pursuing their overall goals. The following section will further the characteristics from the definition and aggregate them into a conceptual framework.

3 Interaction Quality and Community Governance

The focus of this research is how POs successfully engage their members in virtual interaction, thus enhancing the organization's overall and its members' individual performance in achieving the organization's goals. Hence, we consider three constructs of central importance to capture this relation, community interaction quality (hereafter CIQ), community governance, and an independent performance construct. All constructs were developed from existing theory and form the conceptual ground for empirical testing. Coming from research on VCs, a literature analysis formed the basis to aggregate the multitude of aspects on VCs and transferring them to the context of POs. The current framework is illustrated in figure 1. As of now the framework depicts overall relations between constructs. Relations between sub-constructs are object to further analysis, thus we present first assumptions on the interrelation of constructs.
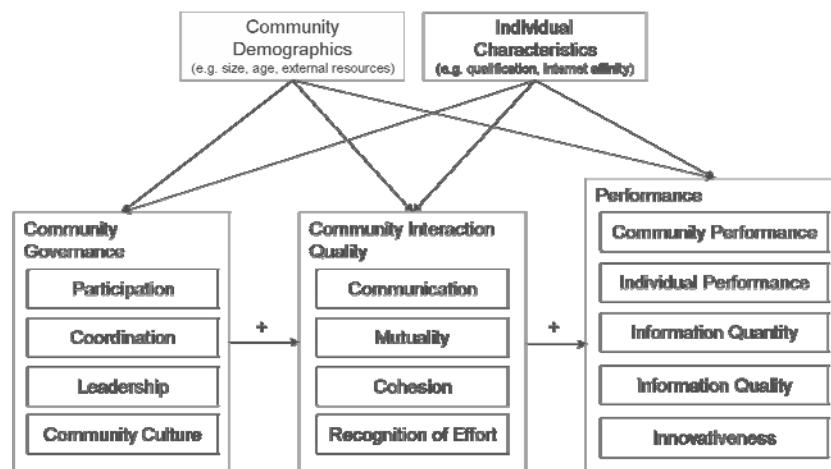

Figure 1: Conceptual Framework.

3.1 Independent Construct: Community Governance

The independent construct is depicting community governance. As VCs, that are privately founded usually do not refer to an existing organizational setup, self-organization and the establishment of governance is crucial. Recently, open source research has begun to investigate the concept of community governance. Until now there is no validated framework addressing the community governance, rather Markus [MA07] wrote about the lack of a consensus with regard to Open Source communities, the „lack of an accepted definition leaves it up to each researcher to decide what OSS governance means, making it challenging for others to assess the research findings" (p. 152). As a result of her study, Markus gives support to a multidimensional construct of open source community governance.

Organizational characteristics shaped by the community governance setup may have an influence on the interaction quality. Thus, it is perceivable that different community governance setups lead to different levels of interaction quality. Several studies examine single elements of community governance structures and analyze their dependencies. Shah [SH06], for example, focuses on "the level of code control held by [a community] sponsor […]" (p. 1009), or in other words aspects of power and property rights. Other examples include aspects of motivation [HE07], as well as leadership, authority, and democracy/meritocracy [MF07].

Here we analyzed contributions from literature with respect to community governance aspects, leading to the identification of four dimensions of community governance: participation, coordination, hierarchy, and community culture.

Participation deals with three major aspects, namely access, roles and motivation. The first aspect can be subdivided into member selection and routines that guide the process of community joining. Virtual communities can decide for themselves how they design their participation structure. They are free to differentiate between their stakeholders' e.g. actual patient and interested public. Moreover, joining can depend on community consent or upon recommendation from another member. Accordingly, identification as one or the other is a requirement to gain access to certain information or functionality of the community. There is also the possibility that a new member cannot exercise all roles or connected hierarchical functions right from the start, but has to gain credits by participation and activity. Studies from the field of open source software development indicate that most new members merely observe in the beginning. They read the older entries and make themselves acquainted with all functionalities. During this time they show an above average intensity in their communicative behavior [KS03, KS02].

Coordination in a virtual community can either be supported by technical means or personal reconcilement. Often, virtual patient organizations also meet personally, thus it is conceivable that a mix of technical and face-to-face solutions are in place. It is however unknown, what exact coordination mechanisms are chosen and why. Coordination can be subdivided into aspects regarding the level of coordination [CK09, HR09], degree of formalization [KM01], and the assignment of responsibilities or tasks [DL06].

6

INFORMATIK 2011 - Informatik schafft Communities
41. Jahrestagung der Gesellschaft für Informatik , 4.-7.10.2011, Berlin

www.informatik2011.de

Most patient organizations are privately founded. Consequently, their organizational form can reach from loosely connected to a registered society. In accordance with this are aspects regarding hierarchy and leadership within the community. *Leadership* issues in the context of open source communities involve the establishment of hierarchy levels, e.g. election of the executive board, control mechanisms, graduated privileges for community members, and the responsibilities of team leaders. An issue strongly intertwined with roles is that of privileges associated with them [KS03, MA07].

Community culture is the binding principle for interaction. There have been numerous studies that address the influence of corporate culture on issues like performance, trust, and many more. Not surprisingly, community culture seems to be related to the outcomes of the community efforts as well. Community culture is based on the personal background of the community members. Therefore shared ethical norms matter as well as a common ideology [CH10, XJ09]. Hemetsberger & Reinhardt [HR09] also point out how problems in a community might rise from differing individual and collective objectives. Besides the shared beliefs and norms, there is the aspect of shown behaviour and sanctions. Thus, each community develops an individual set of explicit and implicit rules and norms that work as an interaction backbone. Especially, new members might face a rough tone if rules are not obeyed or given information has not been read [HR09].

3.2 Mediating Construct: Community Interaction Quality

As we consider successful collaboration dependent on mutual understanding and the facilitation of interaction, we develop the construct of community interaction quality (hereafter CIQ) as a comprehensive concept of the quality of interaction among members of VCs. As central construct of our framework, we consider it to mediate organizational effects on community performance (see figure 1 for illustration). For the purpose of developing this new construct, the paper takes up the concept of team work quality by Högl and Gemünden [HG01] and basis assumptions from social behaviour [HO74] and applies them to the specific situation of POs. Albeit, these two concepts can only serve as a starting point to begin to describe interaction in VCs, but as both depict interaction pattern in groups and individually they seem sufficient to build upon. Still, the context of VCs in context of POs requires additional thoughts, as for example members of POs do not usually share a prior professional or work related relationship [SD07] as members of teams do. As multidirectional communication and voluntariness shape the long-term engagement of members in POs it is conceivable that concepts of leadership structures, hierarchy, and power distribution vary from what we know from team work quality. That said we can already assume the governance mechanisms of POs to be relevant for interaction pattern. Last, members of POs are not reimbursed for their engagement as team members of firms are through their salary. Thus, motivational aspects to participate as well as frequency and intensity of interaction may differ imaginable.

7

As interaction in social behaviour is traditionally studied in terms of frequency and intensity [HO74], it however, may not be sufficient to cover the virtual context. Thus, additional aspects were considered in representing the multi-dimensional construct of CIQ. In context with results of our analysis of VCs, we identified communication, mutuality, recognition of effort, and cohesion as to be the core constructs of interaction quality.

Communication is the most essential facet of CIQ as it provides the means of exchanging information or knowledge, in other words communication is the main facilitator of interaction. It is defined by frequency, degree of formalization, and structure [HG01]. Frequency is directed at how extensively communication with and among community members is (e.g. posting and viewing activity) [KK03]. The degree of formalization refers to the possibilities of engaging in communication of members with the steering board of the community. Structure refers to the possibility of every community member to be able to communicate directly with all other members (many-to-many interaction). Elements enabling many-to-many interaction are considered producing "the dynamics that drive community value" [CO00]. Also, collective reflection that is based on communication "shapes goals and produces collective ideas that go beyond individual thinking" [HR09].

Building on findings from Shah [SH06] and Jeppesen [JE05] we consider support, user-to-user assistance, and reciprocity as the constituting aspects of *mutuality*. User-to-user assistance evolves with the degree of reciprocity and thus determines the communities' shared solidarity [ED01]. Reciprocity is concerned with the dynamics of contribution to the community and receiving back in return [KO99, PR01, SH06]. Stable norms of reciprocity hamper free-riding activities [FS03]. Thus, mutual respect, support, and granting advice when needed [LS06] contribute to a balanced interaction.

Cohesion is caused by the community's purpose. It is the binding principle of a virtual community that attracts members to participate and stay involved. The community's purpose needs to be communicated to all members as it determines the degree to which members "stick" to their community [PR00]. Moreover, as Casalo et al [CC08] could show, the commitment to the community is positively influenced by an interaction that is related to a binding interest and perceived as of emotional value. All of this adds to the concept of "sense of virtual community" [KK03].

Recognition of effort refers to the appreciation of the individual member's contribution by all stakeholders (company and peers). Otherwise the individual member will loose motivation [JH08] to participate. This manifests in the concept of peer recognition [JM03] and recognition from the executive board. It preserves an amicable, positive atmosphere and strengthens social ties among peers. Several empirical studies indicate a strong desire for users to be visibly recognized, e.g. via titles, announcements, etc. [JM03, FU06, JF06].

From considerations on organizational parameters and CIQ we assume that community governance depicts the background of interaction. Thus, CIQ is considered to mediate the effect of organizational aspects on the overall performance.

Assumption 1: Community governance setup is perceived to influence the community interaction quality.

3.3 Dependent Construct: Performance

The outcome of internal collaboration among members of POs can be measured in terms of how the collaboration was able to meet pre-established objectives [CO00, PR01]. POs usually follow various goals that can be subsumed as awareness generation in public and among stakeholders of the health care system, in order to e.g. spark further research on their particular disease, second, provision of information among patients and their kin about the disease itself, and a platform for information exchange, in order to offer support and practical knowledge, as well as emotional support. This coincides with the goal to help improve the patients' quality of life. The perception of collaboration itself depends, in part, on the members' expectations. Thus, it is in the interest of the PO executives to match the POs' goal pursuit with their members' expectations. This will result in an increased community and individual performance.

The dependent construct of *performance* can be defined as the extent to which the collaboration is beneficial to the individual member and the overall development of the community goals [LS06, PR01, CO00]. Moreover, performance can be estimated by applying quantity and quality measures. In accordance with the goal of information provision and dispersion, we will refer to the amount of solution knowledge and information (quantity), as well as the degree to which information can be integrated individually without further effort (quality). Due to multidirectional communication, every member is entitled to post information and their ideas. This can be ranging form the expression of latent needs or problems, concrete ideas or solutions, to drafts or prototypes of viable products [JF06, FJ07].

The process of collective communication and reflection on ideas of others provides collective ideas that exceed individual thinking. The members' collective engagement and mutual encouragement serves as incubator for ideas and solution knowledge. As stated above, members of POs develop a degree of expertise on their disease, but also on their particular problems and needs. Thus, it is reasonable to expect innovative solution knowledge to be existent in POs and members to display individual innovative behaviour. The innovativeness describes whether this innovation outcome is that of incremental, radical, or disruptive nature [JF06], while individual performance addresses the members' innovative behaviour towards the PO. We expect the member structure of POs to represent diverse backgrounds (e.g. regarding age, education) and distant knowledge (e.g. profession, years of professional experience). Although incremental innovation is assumed to predominate, member structure may enable ideas of radical nature as well [CL04, PR04].

9

Finally, we assume that the effect of CIQ on performance is twofold. On the one hand, a high interaction quality is conceived to foster the development of innovative ideas. By means of interaction a promising base of knowledge is formed. Ideas, even when still in vague stages, are communicated and advanced by the community. On the other hand, interaction strengthens the overall and individual performance of the community, retroactively influencing the cohesion, mutual relations, and commitment of members.

Thus we assume:

Assumption 2: A high community interaction quality influences the innovation output.

Assumption 3: A high community interaction quality influences the community and individual performance.

Assumption 4: A high community interaction quality influences the information quantity and quality.

3.4 Controls

As patient organizations as well as their members are very heterogeneous we aim to control for unobserved variance by introducing two sets of variables that target a variety of individual and external aspects. First, *community demographics* subsume different control variables regarding the PO itself. This regards variables such as size of the PO expressed through the current number of members, its duration of existence in years since establishment, and existing claims against available external resources, expressed in public and private financial and material funds. Second, *individual characteristics* control for variables that are specific to the individual member. This covers personal attributes, such as gender, age, family status, as well as information on insurance status. Further, information regarding knowledge, expressed through education, professional classification, and current occupation. Third, aspects regarding the disease comprise if the member is directly affected or a person in care of a patient, the status of current physical and mental well-being, and the perceived knowledge of the disease. Lastly personal internet affinity indicates the usage of virtual interaction.

4 Research Design

In total, five POs of rare and chronic diseases are to be addressed to serve as pre-test for our assumptions before conducting a nation wide survey with a substantial sample of 51 patient organizations. This setting seems appropriate for several reasons. Our empirical design is based on a multi-level analysis. On the community level, information is acquired by qualitative semi-structured interviews as well by external available data about the participating POs. On the individual level, we rely on a questionnaire-based survey, including an average of 30 patients per PO. The study draws on POs rooted in the German health care system, still, aspects of transferability to international health care contexts are considered in the study design.

10

Sample and data collection

Our sample was built from two independent organizations engaged in patient support of rare chronic diseases. Besides general information on rare and chronic diseases these organizations offer lists of patient organizations. First, ACHSE (Allianz chronisch seltener Erkrankungen, alliance of chronic rare diseases) is an independent organization with 105 member organizations[2], which is located in Germany. Second, Orphanet is a European consortium that entertains an online database with patient organizations sorted by country. For Germany, 263 organizations[3] were listed. From a total of 368 organizations doubles were eliminated, leaving 275 organizations for further selection. After establishing the population, organizations were chosen that existed since more than two years. Moreover, POs eligible for the final sample should offer rich information on their websites (indicated by number of topics and sub-pages) and enable many-to-many communication among their members, indicated by offering a discussion forum with at least 100 users registered. A total of 62 support groups met these criteria. In a last sequence, umbrella organizations were eliminated as they only function as aggregation of different groups, leaving a total sample of 51. From these, a random sample of five was selected for a pre-test.

Following we describe our research approach for the planned empirical study. Based on the results an iterative adaptation of the questionnaire is will conducted, leaving the remaining 46 organizations to be addressed in the final study. All POs are accessed by contacting the responsible executives who are then asked to participate in a semi-structured interview that mirrors the corresponding member questionnaire, but is extended by some questions regarding their individual functionality as an executive. With their consent we send our mail and online surveys with a personalized cover letter explaining the purpose of the survey and anonymity of data acquisition. Furthermore, we ask for permission to communicate the survey over regular group channels, such as the homepage, forum, etc. In the questionnaire, we request respondents to answer the questions with reference to their PO. The focus is on the processes, actions, and behaviour in the relationship between individual (member) and the organization (community executives). Simultaneously, additional data about the PO is collected from openly accessible sources, mainly the homepage of the PO.

Scale Development

For constructs with an existing theoretical and empirical base we relied on previously validated measurement items. This mainly regarded aspects of CIQ and performance. Concerning the first, we adopted scales from Yuan and Woodman [YW10], Scott and Bruce [SB94] on innovative behaviour, and Franke and Shah [FS03] in the context of VCs. Regarding the latter, we adapted scales from Högl and Gemünden [HG05].

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2 Number of member organizations listsed for June 2011 http://www.achse-online.de/cms/mitglieder/mitgliederverzeichnis.php

3 Number ob member organizations listed for Germany in June 2011 http://www.orpha.net/consor/cgi-bin/SupportGroup_Search_List.php?lng=EN&type_list=SupportGroups_by_country&lng=EN&search=SupportGroup_Search_List&data_id=0&TAG=DE

11

INFORMATIK 2011 - Informatik schafft Communities
41. Jahrestagung der Gesellschaft für Informatik , 4.-7.10.2011, Berlin

www.informatik2011.de

Where these are not available we develop multiple-item scales, relying on extant research that has studied governance, interaction and innovation success. Based on its definition, we first generate a tentative pool of measures for each construct based on its definition. We then ask four academic experts to critically assess the constructs and their associated items in a two-step approach. First, all items are provided to be grouped, testing for discriminatory power of constructs. In a second session, all constructs and items are made available to be matched, this time testing for specificity and precision of items. Afterwards, adjustments based on the inter-rater agreement are made by application of Cohen's kappa analysis [MB91]. This procedure is repeated three times with four participants each, totalling in 12 experts evaluating the questionnaire. Following, a questionnaire is designed using the remaining items. Again, academic experts and community representatives assess the questionnaire for any potentially confusing aspects and flaws in design. Based on their assessment the questionnaire will be revised to improve specificity and precision.

4 Results

As the research is currently under preparation, we expect to present preliminary results of the study by October 2011 (in time for the conference). Results are expected to provide a better illustration of current status of POs, regarding their organizational characteristics, communication patterns, knowledge generation and dispersion. Further, we expect to display the commonalities and differences in governance structures and interaction patterns in the respective POs. Results should shed further light on how the innovative potential of POs could be leveraged depending on organizational characteristics and the design of collaborative interfaces, leaving potential external third parties with an idea of who they are dealing with and how they can align themselves. We finally discuss if and how our findings may be influenced by national health system characteristics.

5 Conclusions

Virtual communities are considered as the next big opportunity to boost companies' innovation activities [WL08], and this is not limited solely to the open source software movement. By taking into account relevant characteristics of virtual communities, we were able to derive a conceptual framework to examine community governance and community interaction quality of POs, which seem vital to the understanding of VCs. The impact of both is considered to be on the degree of innovation, maturity of transferred content, quality fit, and quantity. The framework and the postulated effects are subject to empirical testing, but we believe that we have created a solid concept and directional setting implications for future research in community collaboration for innovation.

12

As the proposed study only addresses Germany based communities it seems only conclusive to conduct an international survey to compare for effects of the health care system on patient organizations. This will make results more robust and allow for further conclusions. Moreover, a complementing qualitative study may shed more light on specific aspects and allows for more in-depth research.

Also, some aspects are not yet included which may be considered for future research. It can be assumed that dynamics vary with regard to the product or industry the community is evolving around. Hence, surveys addressing a variety of topics from sports equipment [HI06, LU04], clothing or furniture [OP06], to music instruments [JF06] may deepen the understanding for different types of communities. Second, like any social entity, virtual communities change over time [KK04, MM08]. With greater maturity community governance and interaction may evolve as well, leading to different results that allow for longitudinal comparison.

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14

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