Social Networking, Innovation and the Patient as Peer: The Case of *PatientsLikeMe*

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Abstract

Social Networking Sites (SNS) have started to shift from being used primarily for leisure and fun to have more serious purposes. One such more serious area is health and medicine, where lately several disease-specific communities of interest have established a presence on SNSs. In this exploratory paper, we study a health-related SNS called PatientsLikeMe, by using secondary, web-based qualitative data. By applying Benkler's notion of Commons-Based Peer Production (CBPP) we approach PatientsLikeMe as an online participatory innovation platform in the realm of community based, open, distributed and collaborative innovation. We discuss how the features of social networking sites interplay with peer production in order to facilitate innovation. The paper contributes to the theory of CBPP by analyzing the different characteristics of PatientsLikeMe in relation to other examples from the literature.

Keywords: Social networking sites, Open innovation, Commons Based Peer production, Social Media

Introduction

Social Networking Sites such as e.g., Facebook, YouTube and LinkedIn have had a dramatic impact on society over the last decade (Hampton et al., 2011). An SNS is a platform building on web-based services targeting social interaction and user-generated content that allows individual users to build a public (or semi-public) digital profile, link up with other users with which they feel connected, view these users activities, and share comments (boyd & Ellison, 2007; Kane *et al*., 2014; Kaplan & Haenlein, 2010; Treem & Leonardi, 2012). Activities typically featured in SNSs include self-presentation, sharing text, images, and photos, engaging in debates and dialogues, getting updates on activities and whereabouts of friends, and developing and maintaining relationships with others (Park *et al*., 2009). From the SNS owner's point of view, the content and activities of the users is part of the business model in terms of information production (van Dijck, 2013; Tempini, 2015). Starting much as a phenomenon amongst adolescents, SNS memberships has increased dramatically and come to engage also a more mature audience (Hampton *et al.*, 2011). In Hampton's 20011 survey, over half of all American SNS users were 35 years or older.

As SNS usage has become more established and mature, there has also been a shift in focus from purely leisure and entertainment to more "serious" matters (boyd and Ellison, 2013; van Dijck, 2013; Park *et al.*, 2009; Mayer-Schönberger and Cukier, 2013; Kallinikos and Tempini, 2014). Following this trend, many organizations have also started to utilize SNS. One particular use of SNSs is the collaborative organizing of innovation.

Spurred by the increasing digitalization and connectivity, there is a growing interest in various forms of distributed innovations, ranging from firm controlled open innovation (Chesbrough, 2003) initiatives to a more fully distributed form of commons based peer production (Benkler, 2002). Many scholars studying SNS have focused on its impact on marketing and business (Mount & Garcia Martinez, 2014), and little work has been dedicated to research on SNS in context of open and distributed innovation. Adding research to fill this gap is important, since the increasing connectivity in society and social media in particular opens up for innovation models resembling commons based peer production in various new domains. In this paper, we will contribute to this area, and our research question is thus: *In what ways do peer production and social networking features interplay?*

One domain where innovation and social networking seem to meet is healthcare, where several disease-specific communities of interest now exist on SNSs (Hughes *et al.*, 2008; Mayer-Schönberger and Cukier, 2013; Kallinikos and Tempini, 2014). Patients, often with chronic diseases, seek to meet and interact online with other patients with similar problems, both to share clinical information and to provide and receive support. SNSs provide them with an opportunity to build social networks and the social networking features enable patient communities to learn from others about their illness (Kallinikos and Tempini, 2014), and to gain support from peers with similar experiences (Hughes *et al.*, 2008; van Dijck, 2013). One such health-focused SNS is *PatientsLikeMe*, which is targeting improved health for patients with different chronic conditions by facilitating information sharing within disease-specific communities. We will therefore use *PatientsLikeMe* as an illustrative case of how social networking features may interplay with principal mechanisms of peer production.

The paper is organized as follows: next, we position the paper in the open and distributed innovation literature, and give an overview of commons-based peer production as a theoretical foundation, as well as the features of social networking sites. This is followed by method where the selection, collection and coding of data is described. Results are then analyzed and discussed from the principal mechanisms of CBPP, and how SNS and CBPP interplay.

Related Research

There is a growing interest in collaborative organizing of innovation, manifested by a broad terminology directed towards an open and distributed mode of innovation, ranging from firm controlled open innovation initiatives to a more fully distributed form of commons based peer production. Chesbrough (2003) suggested that firms could accelerate innovation and expand market opportunities by using purposive inflow and outflow of knowledge across its boundaries. The openness here refers to a controlled exchange of ideas and intellectual property with external stakeholders such as customers, suppliers, partners or competing firms, often by the use of techniques such as innovation contests and crowdsourcing (Howe, 2008; Surowiecki, 2005) and exploitation of online communities (Dahlander and Magnusson, 2005; Rolandsson *et al.*, 2011). One particular external source for innovation is the consumer or user of a product. In user-driven innovation, advanced users can develop solutions more close to their needs than a firm's R&D

department. Such lead users has been claimed to be the main external source for innovative and value-adding contributions in many industries (von Hippel, 2005; Lettl *et al*., 2006; Piller and Walcher, 2006). Lead users engage in innovative tasks by their own initiative, and for firms the challenge is to take advantage of them.

An illustrative example of a voluntaristic and alternative model to organize innovation and production is open source (Lakhani & Panetta, 2007). The typical open source project is based on a loosely coupled community, where work is totally delegated, relying on a high amount of voluntaristic contributions, coordinated by one or a few developers. Open source can in its purified form be described as a production mode where the outcomes as well as the required knowledge resources are considered as common resources, and where the aim of the process is to contribute to public good. Over the last decade open source has to a large extent has been intertwined with the commercial software market, leading to a plethora of new business models and new sorts of software suppliers. While individual developers contributing to communities do so by a complex set of social motivations, guided by the norms and values established in open source communities, firms engaged in open source tend to be driven by economical and technical motivations, trying to appropriate value from public good (Kogut and Metiu, 2001; Rolandsson *et al.*, 2011).

One attempt to explain this development towards distributed innovation is Benkler's notion of commons-based peer production (Benkler, 2002). The predominant understanding of the organizing of economic production is that individuals engage in productive activities either as employees in firms, following the directions of managers, or as individuals in markets, following price signals (Coase, 1937; Williamson, 1975). Benkler (2002) describes commons-based peer production as a third mode of production, where large aggregations of individuals independently are searching for opportunities to be creative. Contrary to hierarchical authority in firms and the price signals of markets as coordination mechanisms, Benkler (2015) argues, that commons-based peer production is based on the coordination of a critical mass of voluntaristic independent contributors that are self-allocated and engage in self-managed tasks.

This new mode of production may not conquer the old modes, but rather tend to co-exist and rely on firms and markets, resulting in blurred boundaries between value creation and value capture, in what could be described as a value ecosystem. Collaborating firms are enabled to capture, elaborate on and capitalize value created outside the company, but may also be obliged to contribute to value creation where the appropriation of invested resources are out of control (e.g., Chesbrough and Appleyard, 2007; Dahlander and Magnusson, 2005). This joint development of value creation is still an emerging phenomena where the borders between commons-based and proprietary; open and closed; firms and communities; peer production and market are not always clear cut.

Furthermore, the increasingly digitalized society opens up for innovation models resembling commons based peer production in many domains beyond software, such as 3d printers, biotech, and mobile phones (Cahalane *et al*., 2013; Hilgers *et al*., 2010; Remneland *et al.*, 2011). One interesting domain is healthcare, where several disease-specific communities have emerged on social networking sites (Hughes *et al*., 2008; Mayer-Schönberger and Cukier, 2013, Kallinikos and Tempini, 2014). Patients, often with specific diseases, seek to meet and interact online with other patients with similar problems, both to share clinical information and to cope with their situation. This has led to specific SNSs that provide patients with an opportunity to share information about their own situation and to learn about their illness together with other

patients, but also together with researchers and medical experts that participate in these forums (Kallinikos and Tempini, 2014).

PatientsLikeMe has been studied from a health information-sharing perspective (Lustria *et al.*, 2009; Wicks *et al.*, 2012; Kallinikos and Tempini, 2014). However, *PatientsLikeMe* is a for-profit company that, in addition to facilitating patient networks for advice and comfort, also generates, collects, and sells aggregated patient data for instance longitudinal drug efficacy discovery through virtual clinical trials (Wicks *et al.*, 2011), about the real-world nature of disease amongst its network of trusted partners (researchers, pharmaceutical companies, nonprofits developers) in order to invent new treatments and drugs (Wicks 2007; Wicks and Frost, 2008; Turner *et al.*, 2011; Kallinikos and Tempini, 2014). This means that each *PatientsLikeMe* tool offers research services through variety of tools that allow users to track, describe and share personal medical data in addition to symptoms and treatments. *PatientsLikeMe* is thus more than just a regular SNS (Tempini, 2015) and it has been described as a hybrid blend of pursuit of health care information in web-based context to innovative amalgamation of patients networking (Tempini, 2015; Kallinikos and Tempini, 2014).

Commons-Based Peer Production

In the following, we present the essential characteristics of CBPP (Benkler, 2002; 2015; Hilgers *et al.*, 2010), in terms of three dimensions:

- Decentralization: Decentralized conception and/or execution of problems and/or solutions

- Motivation: Ability to motivate people to contribute, including a wide range of motivations

- Organization: Governance and management is separated from property and contract

Decentralization. The decentralized conceptualization and execution of both problems and solutions is crucial for pure CBPP. The process is dependent on a diversity of coordinated actions by different contributors. In open source anyone can find a bug and try to fix it, or develop a new functionality that they propose to be included (Fitzgerald, 2006). In Wikipedia anyone can start a new entry and add or rewrite the content of an existing article (Forte *et al.*, 2009). In CBPP, tasks are broadcasted either by individual contributors or a focal coordinating organization (Hilgers *et al.*, 2010). In firm-hosted CBPP the initiator would typically be a firm or an organization. This is similar to other open innovation approaches such as crowdsourcing and innovation contests (Surowiecki, 2005), where the problem owning organization or a mediating broker designs the task (Feller *et al.*, 2012). For decentralization to work, problems/tasks must be modular and possible to separate into parts that are possible to solve separately. The degree of granularity could vary, as the complexity of tasks. Tasks may range from highly specialized, requiring expertise and domain knowledge, to the sharing of personal information and experience. For example, NASA click-workers contributed by providing physical resources in the form of unused CPU-time from home computers. Key factors for decentralization are: What is a task (i.e. problem)? Who designs a task? What is a solution? What is execution of solutions? Who executes solutions?

Motivation. The ability to harness a wide range of intrinsic or extrinsic motivations in order to mobilize a critical mass of contributors, is crucial for successful CBPP projects. The motivations could be non-monetary as well as monetary. For example, MTurk is a commonly known monetary crowdsourcing platform (Horton and Chilton, 2010), and ReCAPTCHA is an example of non-monetary. A diverse set of motivations to contribute has been addressed in the open source literature, e.g. reputation, fun, ideological reasons, professional (see von Krogh *et al.*,

2012). Rewarding participants that contribute to innovation communities is an essential aspect of crowdsourcing literature (Feller *et al.*, 2012), where rewards could be monetary or take other forms. In user driven innovation, the driving force is the need for a better version of a product you are using (von Hippel, 2005). Pure CBPP is typically assumed to rely on voluntaristic work, where other motivations than the economic are essential drivers. Key factors for motivation are: What motivates different actors to contribute? What could spur or disturb motivation?

Organization. The third criterion, separation of governance and management with property and contract, is another important characteristic of CBPP. This is different from what could be regarded as firm centric open innovation (Chesbrough, 2003): "The use of purposive inflows and outflows of knowledge to accelerate internal innovation". Here, contracts between different actors that provides inflow or outflow are important parts of a more controlled and purposive management of innovation. Similarly, in crowdsourcing the problem owning organization is designing the task, deciding on the rewards and largely orchestrating the process. For a firm that engages in CBPP the degree of control is generally much lesser. Governance could take different forms here, like owning the platform that people contribute to, or owning the tool kits or networking platforms essential to the CBPP community at hand. To be pure CBPP, the governance mechanisms should be separated from ownership or proprietary claims. Inputs and outputs are governed as open commons or under common property regimes, as for example open source under a GPL license. Resource and task allocation are not based on proprietary or contractual models, but rather based on participatory, meritocratic or benevolent dictatorship/charismatic models. Essential factors for organization of CBPP are: What governance mechanisms are in place? How are decision procedures working? How is coordination managed? What social sanctioning mechanisms are there? What intellectual property regimes are in place? What claims are made?

Social Networking Sites

For CBPP to work, digitally networked environments are essential. Typically this include the Internet and web based services. SNS has become a technology that is growing in importance for CBPP. In our study we consider SNS as a subgroup application under the umbrella of social media and refers to a group of web-based services that allows users to create, edit, share and commenting the content among participants (Kaplan & Haenlein 2010; boyd and Ellison 2007). SNSs such as Facebook, LinkedIn, Flickr, Instagram and YouTube have, together with a plethora of other applications aiming at communication, collaboration and maintaining social relationships, become an important part of many people's everyday lives (Faraj *et al.*, 2011; Faraj and Azad 2012; Treem and Leonardi, 2012; Bergquist *et al.*, 2013). SNS typically allows individuals to construct a public profile, articulate a list of other users with whom they are connected, and also view their list of connections (boyd & Ellison, 2007; Ellison et al., 2014). This possibility for users to explore other people's profiles, as well as their social networks, can create unexpected latent ties that facilitate rapid and spontaneous community building (Haythornthwaite, 2005; Haefliger *et al.*, 2011; Schau and Gilly, 2003).

SNSs are highly decentralized in the sense that anyone can create an account, set up a profile, and start expressing opinions. Although an SNS "user" is typically understood as an individual, groups and organizations can also be users. An SNS provides a plethora of features to make their users seen and heard; text, images and/or video clips can be uploaded and made visible to other community members typically through status updates. In 2011, Facebook introduced Timeline; a new kind of profile that would help the users tell their stories (Lessin, 2011). Telling

one's story or sharing one's experiences are central SNS features, and since the user decides what to upload and share with the community, the users are empowered to profile themselves as they see fit.

SNS's self-expression features appeal to people's intrinsic motivation to communicate personal insights but studies have also revealed that (some) users may be more interested in belonging to a community or supporting a cause (e.g., Smith, 2010). Hence, SNSs have features to support the creation of sub-communities focusing on specific issues or interests, and by joining such groups, the user is immediately associated with that cause. Since all activities typically are visible to others, the joining of a group sends a signal to one's peers. Members can often see each other's profiles and learn what subgroups one belongs to. Other ways for SNSs to provide more extrinsic motivation is to provide mechanisms for feedback. Typical social networking site's features are summarized in table 1.

Table 1 Typical Social Networking Site Features

Typical SNS Features	**Illustration in Scientific Literature**
Status update List of friends and friends of friends profiles Like Comment	Boyd 2010; Treem & Leonardi 2012; Leonardi et al., 2013; Ellison et al., 2014; Farzan et al., 2008; Hotzblatt and Tierney, 2011; et al., 2011; Zhang et al., 2010; Muller, and Millen 2008
Catalogs of photos and entries Contributions are searchable History of activities and discussions recorded	Kane and Fichman, 2009; Poole and Grudin 2010, , Mejova et al., 2011; Muller, 2007; Treem and Leonardi 2012; Leonardi et al., 2013
Revision of own content Contributions by others can be deleted Contribution on own site can be deleted	Dugan et al., 2008; Farzan et al., 2008; Yates et al., 2010; Thom-Santelli et al., 2008; Treem and Leonardi 2012
Relations to others displayed Following Subscriptions Tags (e.g. #) to show contributions to topic	Zhang et al., 2010; M. Muller, 2007; Farzan et al., 2009, Freyne et al., 2010, DiMicco et al., 2009; Treem and Leonardi 2012, Leonardi and Meyer, 2015; Lampe et al., 2007; Ellison et al., 2011; Gerlitz and Helmond, 2013
Alerts Votes Up	Menon and Phillips, 2011; Koroleva et al., 2011; Gray, 2011; Janis 1972; Leonardi et al., 2013; Majchrzak et al., 2013
Re-visibility Activity Log	Faraj et al., 2011; Leonardi et al., 2013, Treem and Leonardi 2012; Majchrzak, et al, 2012; O'Mahony & Ferraro, 2007; Majchrzak et al., 2013; Leonardi, 2014

Entries made by users can be commented on by other users, and "Thumbs-up" or "Likes" may be offered to various sorts of posts. Such explicit feedback indicates to the user that his or her entry has been seen and (possibly) appreciated by others, and this is known to stimulate further

participation. The fact that the number of "Likes" is publicly made visible is another feature that increases peer pressure to compete for popularity and thus motivates people to share (interesting or "cool") stuff (Zhao *et al*., 2008).

The ability to create groups or sub-communities within an SNS gives the users a certain degree of governance power. As the creator of a group, you may decide as to whether the group should be visible or hidden and whether it should be open to everyone or only to selected invitees. However, the site owners may exercise overriding powers when so deemed appropriate, and - just as moderators in threaded discussion forums - shut down groups, ban users, or censor content. Such social sanctioning may also occur between members as many SNSs have features not only to link people together, but also to block, disconnect or "un-friend" members with whom a user no longer wants to be associated.

Methodology

Setting: The case of PatientsLikeMe

PatientsLikeMe, according to *PatientsLikeMe*' official web site, is a United States based social networking platform that allow patients to cope better with their health conditions, exchange personal health information and discuss common symptoms. *PatientsLikeMe* revolves around a three-dimensional data-sharing platform that contains sharing, support and research. Through its online community features, patients establish a network where they connect and collaborate with the people like themselves. Till the 6th April 2016, PatientsLikeMe had more than 400,000 plus members. *PatientsLikeMe*'s members share their disease experiences over 31 million data points about 25000 plus different conditions, including ALS, diabetes, depression, fibromyalgia, multiple sclerosis, and psoriasis amongst other. Starting out as a collaboration between three MIT engineers with a sick brother and friend, *PatientsLikeMe* is today a for-profit company that considers it their mission to align patient and industry' interests through data-sharing partnerships. This means that data that is voluntarily provided by the patients is aggregated and shared with trusted nonprofit, research and industry partners who use it to improve products, services and care for patients. *PatientsLikeMe* has a clear innovation focus as the management team believes that their site can improve patient care, transform the manner in which patients manage their own conditions, and ultimately change the way industry conducts research. (*PatientsLikeMe*'s website: www.patientslikeme.com).

Data collection

In researching a semi-closed online phenomena like *PatientsLikeMe*, where first-hand observations can be difficult, secondary data becomes an important resource. Cowton defines secondary data as "data collected by others, not specifically for the research question at hand" (1998, p. 424). The primary advantage of secondary data is the low cost that comes from the fact that the data already exist. The trade-off is that the researcher does not have control over the data production (Cowton, 1998). Secondary data has also been used frequently in information systems research (cf. Freeman & Jarvenpaa, 2000; Romano et al., 2003). We have used six different sources of secondary data and complemented it with email questions (see Table 2).

Table 2 Web-based Qualitative Data Sources

Sources	*Descriptions*
Recorded talks of *PatientsLikeMe* officials (TED, TEDx, TEDMED)	• Two talks by co-founder and President Benjamin Heywood (2011: 12 minutes and 2013: 16 minutes). • One talk by Co-founder Jamie Heywood (2014: 49 minutes). • One talk by R&D Director Paul Wicks (2015: 23 minutes). • Three talks by Health Data Integrity Manager, Sally Okun (2013: 7 minutes, 2012: 52 minutes and 2012: 3 minutes)
Testimonials collected from *PatientsLikeMe* website	• 51 formal statements by patients, partners, researchers, and physicians (anonymized by using letters, e.g. patient A)
Publically available interviews	• President Benjamin Heywood, Chairman Jamie Heywood, Chief Marketing Officer David S. Williams III and R&D Director Paul Wicks (2011: 15 minutes) • Co-founder, Jamie Heywood (2012: 13 minutes)
Published academic papers	• 38 peer-reviewed medical papers and book chapters using *PatientsLikeMe* as a research case
Blog posts and Press releases from the *PatientsLikeMe* website	• Blog posts from blogs.patientslikeme.com (total number of posts: 3001) • 69 press releases from November 30, 2006 to November 17, 2014
Blog posts and articles from independent websites	• 117 articles and blogs from multiple web-based sources: • Highly profiled group-edited blogs about science and technology's impact on health-care such as Scienceblogs.com, pmlive.com, ihealthbeat.org, rwjf.org, commonhealth.wbur.org, cbsnews.com, and thegovlab.org • Highly profiled tech news and analysis websites that covers ethical and privacy issues of data sharing and money making strategies by *PatientsLikeMe* in wired.com and fiercebiotechit.com • General magazines and newspapers including BusinessWeek.com, WSJ.com, NYTimes.com, sciencebasedmedicine.org, forbes.com, Foxbusinessnews.com, washingtonpost.com and theguardian.com
Personal email conversation with *PatientsLikeMe*	• Six email messages exchanged between *PatientsLikeMe*'s customer representative and one of the authors

Data analysis

Building on Miles and Huberman's (1994) principles of data reduction, data display, and conclusion drawing, we have used Romano *et al.*'s (2003) similar method of dealing with web-based qualitative data, referred to as elicitation, reduction and visualization. Elicitation, meaning

collecting the data, has been reported above. Reduction is an iterative process of selection and coding (Romano et al., 2003). Having identified that *PatientsLikeMe* resembled many of the characteristics of commons-based peer production (Benkler, 2015), the first round of reduction took place during a coding process, where we went through the data and mapped it to the first three criteria of CBPP: task, motivation, and governance. While identifying these main categories, we also searched for sub themes. In a second round of reduction/coding, we looked more exploratively for social networking features exploited by *PatientsLikeMe* and tried to relate them to CBPP theory. This was not a linear process was not linear, but instead we constantly and iteratively moved between what Strauss and Corbin (1998) refer to as axial and open coding. In the concluding visualization phase, we arranged the data in tables and compared and contrasted the firm perspective with the peer perspective, and *PatientsLikeMe* as CBPP with *PatientsLikeMe* as SNS, which lead us up to a discussion of the data from these two dimensions.

Results

The result section is structured based on the three main dimensions in CBPP as described in the theory section.

Decentralization: Conceptualization of problems and solutions

The problem at heart of *PatientsLikeMe* is chronic diseases and serious health conditions. That was what first inspired the creation of the site, as expressed by the co-founders:

> *"Our brother Stephen was living with ALS and we thought, 'there has to be a better way.' There is. By sharing our experiences, we can all contribute new data that can accelerate research and help create better treatments. Our experiences can actually change medicine… for good"*. (Jamie & Ben Heywood Co-founders, PatientsLikeMe).

Patients and their families give and get support and share their experiences with other in similar situations. Much of what is done in *PatientsLikeMe* can be considered as subtasks to these overarching goals, and in that sense, the patients define what the important problems are.

> *"We can do much better fighting the disease as a group than we can as individuals. PatientsLikeMe has been extremely helpful in helping me understand I'm not alone"*. (Testimonial by Patient A, April 14, 2013).

As an SNS, *PatientsLikeMe* offers a platform for patients to engage in a community, which is considered valuable. The *PatientsLikeMe* site is constructed around two separate but interlinked features: a) *PatientsLikeMe* dashboard, b) Open Research Exchange (ORE) platform. The *PatientsLikeMe* dashboard hosts the traditional SNS features, plus a plethora of embedded specialized applications (e.g., Compare Treatment Report (CTR), and Clinical Trial Tool (CTT)). The dashboard is a tool which allows patients to share their medical experiences. In first generation of the dashboard, users were allowed to be anonymous, the shared information was not always very specific, and patients were not able to follow other similar patients. The dashboard merely supported patient members to offer empathic support in small sub-groups.

> *"When dealing with rare diseases, you learn so much more when you start connecting and you find that maybe a problem, like a fever, is a normal part of the illness and people just haven't gotten together to figure it out. Being able to share that information relieves a lot of stress for families"*. (Testimonial by Physician, Dr. Jim King, Children's Hospital Eastern Ontario August 20, 2012).

A challenge with the Compare Treatment Report (CTR) feature was lack of timeline or illness history displayed to patients and peers. Therefore, *PatientsLikeMe* started integrating SNS features, such as track, and learn for enhancing the dashboard' overall functionality and include the ability for patients to find and follow peers with similar profiles. This transformation from first generation of *PatientsLikeMe*'s dashboard to first generation of *PatientsLikeMe*' social networking site helped overcome some of these challenges by introducing SNS features as an integral part to *PatientsLikeMe* dashboard. The combination of CTR and the Clinical Trial Tool (CTT) devise a strategy to chart patients' health to display and track the illness history over time. As an output, CTT enables "routine collection of structured disease, treatment, and lifestyle data, rather than just free text comments" (Weather all and Wicks, 2013, p. 1).

The sharing of information and linking up with other patients create value for the *PatientsLikeMe* users themselves, and therefore provides an incentive for participation. The members (patients and their family members) thus execute the solution to the problem of feeling isolated and not knowing enough. Once they have found how shared information has helped them, they typically want to return the favor by exposing their own stories and data.

"As for donating data, I am happy to do it. The treatments and techniques that I am benefiting from today were developed with information from patients who came before. Sharing my information, is the best way I can think of to pay it forward". (Testimonial by Patient B, March 14, 2014).

The transformation from first generation of *PatientsLikeMe*'s dashboard to first generation of *PatientsLikeMe*' social networking site overcome the challenge that is to provide the solution to the problem, by introducing SNS features as an integral part to *PatientsLikeMe* dashboard. While posting and commenting on their medical experiences, patients collaboratively create an enormous amount of data about the nature of their disease, symptoms of their condition, and real-time effects of their treatments. This traditionally private and personal data is made available as shared data to allow for other patients to learn from peers with similar conditions.

"PatientsLikeMe may also periodically ask Members to complete short surveys about their experiences (including questions about products/tools and services). Survey responses are analyzed, combined with members' shared data and shared with and/or sold to partners. Member participation in these surveys is not required, and refusal to do so will not impact a member's experience on the site". (PatientsLikeMe website, privacy policy).

This voluntary exposure of patient data for research purposes has become a key feature of the *PatientsLikeMe* operation and makes a very valuable contribution to the research community. Collecting data through traditional means, i.e., having patients come to the physician to fill in a form or a questionnaire, is too slow and time consuming.

"The members of PatientsLikeMe don't just share their experiences; they quantify them, breaking down their symptoms and treatments into hard data. They note what hurts, where and for how long. They list their drugs and dosages and score how well they alleviate their symptoms". (PatientsLikeMe website, privacy policy).

The patient information can be medical documents, lab results, and biometric or activity data from smartphones or wearable devices, but also be more subjective information, like health apps in which people report how they feel or social network conversations about health. The structured data goes directly into the ORE (Open Research Exchange) platform, and the

unstructured data, i.e., anecdotes and stories, is visible for others to add to and react on. Patients do in some occasions also take the initiative to design tasks and contribute to solutions for more generic research missions.

"Meet Tam, a PatientsLikeMe member living with MS. She realized that the smiley face pain scale wasn't helping her communicate effectively with her doctor. So she decided to create a new measure that focuses on how pain affects daily functions". (PatientsLikeMe's ORE, web page).

Motivation

The motivation to participate in *PatientsLikeMe* spans a broad spectrum, and may differ among different stakeholders. For patients, the core motivation seems to be personal. They want to contribute to problem solving that may gain them or their relatives situation.

"Sharing my health information with the community is part of being an advocate. If I am willing to be transparent, hopefully others will be inspired to do the same. Together, we are soldiers in this battle against MS..." (Testimonial by Patient C, February 7, 2014).

A customized application named 'Light' motivates the patients though association feature with illness and encourages to share information about ongoing treatments' discussions. Associations improve the dashboard's ability to support patients with tied social connections.

"PatientsLikeMe is a great way to connect (linking) with others living with MS, to compare symptoms and offer suggestions. I use it as a helpful tool to track my disease progression, keep notes, and learn from others". (Testimonial by Patient E, April 29, 2013).

In addition, patients are also motivated to contribute to research that can gain many people. Such as the collected data is helping with research and for better understanding what the disease does, what works better for particular problems.

"I feel very excited that the information being used from my situation will contribute to research to help other people. Without that data, the research will not continue to grow". (Testimonial by Patient D, April 21, 2010).

PatientsLikeMe also provide several mechanisms to increase patients' motivation to contribute in new data, such as giving away t-shirts, and a rating system based on number of followers and contributions. One, two or three stars are awarded to contributors but only a few top contributors get as many as three stars. *PatientsLikeMe* may also add enthusiastic comments to member with high activity.

"When you get all 3 stars, you'll not only have the big picture of their own health, they will help others learn from peers' real-world experiences. Your voice will accelerate real-time research that can help everyone live better lives". (PatientsLikeMe, dashboard for patients' engagement, side note beside patient profile on website).

In addition to this, in a survey Grajales *et al.* (2014) explicate the most common motivations for patients to join was to compare own experiences with others (93 %), share experiences in order to help others (92 %), and get support from others (84 %), as well as track their health over time (82 %). Most patients kept their data within *PatientsLikeMe*. Some shared

their profiles with spouses (29 %), friends (23 %), health care providers (19 %), or patients outside *PatientsLikeMe* (16 %).

There are also built-in features to search for matching profiles with various filters than can be applied to tailor the results to one's desires. Should there be no patient in the system matching certain conditions, alerts can be set up to notify the user when such new patients join the site.

"On the Patients tab, you can search for patients just like you using filters such as condition, gender, age, treatment and more. Now, you can also save your searches and get an email notification anytime someone who meets your search criteria joins. Simply click the yellow bell icon to turn on these alerts". (Value of Openness blog, Posted August 3rd, 2011*, by PatientsLikeMe).*

For scientists, motivation to take part of *PatientsLikeMe* seems partly to get access to patient centric data and to spur and elicit patients in research projects for multiple contributions. Such contributions span from earn and deal with serious illness to considering patients' insights for developing better services and medication together with patient centric devices.

"At Genentech (a biotech company), we come to work every day with the goal of transforming patients' lives. The collaboration with PatientsLikeMe will allow us to learn more from patients with serious diseases, and better integrate their insights into our decision-making". (Testimonial by Partner and Physician, Bruce Cooper, M.D. senior vice president, Medical Affairs, Genentech April 7, 2014).

For pharmaceutical companies the motivation could be both goodwill and the access to patient data. During the research process of developing new medicines and new treatments these motivations are important for pharmaceutical industry, for instance how the treatments are used in the real world, and simultaneously facilitates the patients to have personalized medicine.

"By understanding how patients are using and faring on their products, life sciences companies can truly become patient centric". (Jamie Heywood, Chairman and co-Founder, *PatientsLikeMe).*

Another motivation from pharmaceutical perspective is that they may engage patients through better understanding of what patients are going through and what they value in a treatment being transparent: *"...the key lesson is that if a pharmaceutical company is transparent, it can engage patients"* (Deloitte, Report: "Social networks for life sciences", 2010).

Organization and Governance

Organizational and governance issues are essential for CBPP to work, such as coordination, decision making, and intellectual property regimes.

The organizational form of *PatientsLikeMe* is a firm linked to a network of partners, and a large patient community. *PatientsLikeMe* describes itself as "a for-profit company with a 'not just for profit' attitude" (*PatientsLikeMe* corporate FAQ). It is owned by four investors - *CommerceNet, Omidyar Network, Collaborative Seed and Growth Partners LLC, Invus, LP.* It does not allow advertising on its site. The company has based its business model around aligning patient interests with industry interests. *PatientsLikeMe* scrapes its communities' data, and sell to corporate partners. This business model is not allowed to deviate from the purpose of *PatientsLikeMe*.

"PatientsLikeMe provides Shared Data in individual and aggregate format, to Partners and other third parties for use in scientific research and market research. When selling this information, PatientsLikeMe removes Members' Restricted Data to reduce the likelihood of re-identification prior to sharing information with Partners". (*PatientsLikeMe* website, privacy policy).

PatientsLikeMe is professionally organized in five sections that collaborate: management, research, patient experience, technology and marketing. The research team consists of 20 research scientists that codes and analyzes the patient-reported information. The patient experience team maintain the user interface, and also include consists of community moderators that facilitate interaction among members. Technology support site functionality, and marketing engage and support members and partners. *PatientsLikeMe* has more than 50 partners coming from nonprofit organizations, academia and pharmaceutical/health industry. The overall mission of *PatientsLikeMe* is to provide more efficient development of healthcare and pharmaceuticals, by adopting an open data and patient centric approach.

"Open data helps us accelerate the pace of research, and it's crucial we do everything possible to match patients to trials that might advance treatment and help them live better with their condition". (Paul Wicks, R&D Director at *PatientsLikeMe*).

To some extent one can say that the patient community is self-organizing. However, it is the *PatientsLikeMe* site that supports the organization into specific disease oriented communities like HIV, ALS and MS. Patients can influence which disease communities should be included, but *PatientsLikeMe* that has final say. Coordination and decision making is essentially performed by *PatientsLikeMe* as firm rather than distributed among peers in the community.

PatientsLikeMe has an openness philosophy. However, the data of *PatientsLikeMe* is not public to anyone, it is only accessible to participants and partner organizations, and protected by a firewall. It is thus not fully open as in open access or in GPL based open source. Just like with many other SNS the user cease to have exclusive right to her own content, by agreeing to the terms of use. When people register to *PatientsLikeMe*, they agree that the personal information they share, could be used for multiple purposes by the *PatientsLikeMe* team, like be sold to partners.

"To become a member and access the area on this Site reserved for members [...] PatientsLikeMe requires that you are either a (a) diagnosed patient of the particular community you are joining or a parent or legal guardian acting for such a patient who is under 18 years of age or incapacitated; (b) caregiver for a patient eligible to join such community; (c) healthcare professional (e.g. doctor, nurse, health researcher, etc.); (d) guest with legitimate, non-commercial reasons to participate in the community and who agrees to respect the privacy and preserve the dignity of all community participants or (e) guest as authorized by a PatientsLikeMe member or employee". (Terms and Conditions of Use Effective July 26, 2011)

This means that members should not have any commercial interest in taking part in *PatientsLikeMe*. That is exclusively for partners.

Data is either shared data which typically is anonymous medical data or restricted data such as name and email. As shared data could be considered the main asset for value capture for *PatientsLikeMe*, it is clearly stated that members should expect these to be traded, and that *PatientsLikeMe* has full control over them. Both shared and restricted data are properties of

PatientsLikeMe, and could thus be assets that is transferred in a merger or acquisition of *PatientsLikeMe*.

"Members should expect that every piece of information they submit (even if it is not currently displayed), except for Restricted Data, may be shared with the community, other patients, and Partners". (PatientsLikeMe website, privacy policy).

The propriety of selling sensitive information is not uncontroversial, as was showed in a lively debate at the *PatientsLikeMe* website sparked by a blog post where President Ben Heywood reminded that *PatientsLikeMe* sells data. The company says most of the 350 responses to the blog post were supportive, but a total of 218 members quit.

"It was very disturbing to know that your information is being sold," (Testimonial by Patient F).

However, data is not sold for marketing purposes, as is a common case for casual social networking sites. In order to make patient experience more structured and simple to share, additional various generic SNS features, such as 'join forum discussions' and 'find patients like me' were developed and integrated into PatientsLikeMe's dashboard. By joining forum discussions patients learn and comment their opinions and experiences on the forums' posts and these comments are also visible to their healthcare teams. Patients may follow other similar patients to stay up to date around the topics they are interested in. Patients can build their own list by clicking the follow button as they find patients, topics or organizations that interest them. Patients may see all their updates in MY feed page. With the usage of SNS feature find patients like me, patients find other similar patients with the same disease and symptoms and learn what options are visualized and packaged for better treatment.

"When you find a site like PatientsLikeMe and you realize that there are literally tens of thousands of people that share your condition and your struggle. They are there to reach out, share a laugh, share fun, talk politics, whatever it is, answer a question about medication, you realize you really aren't in this fight alone. You're not the only one that has these symptoms. It opens up a whole new world for you and it takes an awful lot of the fear away from what you're going through". (Testimonial by Patient G, November 15, 2013).

The second part of the PatientsLikeMe site is their integrated research platform; the Open Research Exchange (ORE). ORE is an integrated collaborative platform for hosting research projects in health and medicine. Patients could be engaged in developing new tools to measure diseases and for researchers to enhance the medical research. A Patient Reported Outcome (PRO) is a way to report patients' experiences:

"...PRO is an example of a tool that allow patients to gain increased knowledge about conditions, (activity log) symptoms, treatment options and side effects". (Banerjee et al., 2013).

Another related issue is the means by which *PatientsLikeMe* can protect privacy of member data. *PatientsLikeMe* communities are closed, and the *PatientsLikeMe* site is protected by firewalls, preventing search engines to index the content.

"Members should know that PatientsLikeMe takes commercially reasonable technical precautions to help keep Member data secure". (PatientsLikeMe website, privacy policy*)*

An incident that has been called the scraping controversy illustrates the challenges in protecting privacy.

"Recently, we suspended a user who registered as a patient in the Mood community. This user was not a patient, but rather a computer program that scrapes forum information. Our system, which alerts us when an account has looked at too many posts or too many patient profiles within a specified time interval, detected the user. We have verified the account was linked to a major media monitoring company, and we have since sent a cease and desist letter to its executives. [...] While this was not a security breach, it was a clear violation of our User Agreement (which expressly forbids this type of activity) and, more significantly, a violation of the community's trust". (Ben Heywood's blog, *PatientsLikeMe'* website).

PatientsLikeMe claimed that restricted data (i.e., account information such as names and emails) was not threatened. Rather, it was described as a violation of the user agreement, and of the communities' trust, and that the information that was "scraped" probably was to be sold as part of the scraping company's Internet monitoring product.

Discussion

We have tried to understand the relationship between the features of social networking sites and innovative peer production. Our case - *PatientsLikeMe* - incorporates features from several phenomena from the open and distributed innovation arena. In the following discussion, we analyze *PatientsLikeMe* first from a peer production perspective and thereafter from a social networking feature perspective. Finally, we return to our research question and look at how peer production and social networking features affect one another more generally.

PatientsLikeMe as Commons Based Peer Production

Problems and solutions can be considered at different levels in *PatientsLikeMe*. On the individual level, patients decide what they perceive as their problems. They are engaged with managing their own illness, and reach out to a community of patient peers with similar problems for help. 'Solutions' here could be advice and the sharing of experiences concerning certain drugs and treatment shared via status updates or patient-added files and data. The *PatientsLikeMe* site is explicit in saying that information on the website provided by members should not be considered as professional medical advice. Patients can also contribute at a higher level of research and development. They can find out about clinical trials going on anywhere in the world, they can participate online. Sometimes patients can initiate their own research programs or take on core roles in research projects. This means that the conceptualization of problems and solutions at this level could be considered as a pure peer process among patients, supported by the social networking features incorporated in the *PatientsLikeMe* site design.

At *PatientsLikeMe* site level, partners have access to the *PatientsLikeMe* community to recruit members to research projects. At this level, problems and solutions concern the development of new drugs and treatments, or the evaluation of different measures. Task design and conceptualization of these problems are rarely designed by patients, but rather by the researchers, or by the *PatientsLikeMe* team itself in designing the routine collection of structured disease, treatments and/or lifestyle data. The patients still contribute with personal data that goes into specific research projects or *PatientsLikeMe's* large database of structured data, as well with suggestions for improvement of different treatments and measures ranging to fully patient initiated innovations. However, the peer process at this level is more firm centric, with the *PatientsLikeMe* team as the ultimate task designer.

In sum, when it comes to decentralization, we find that things are not necessarily black or white. The conception of problems and solutions *is* decentralized in some sense but is *also* firm-centric in another sense. The decentralization at the individual level appears attract users and persuade them to enroll whereas the firm-centric conception of the overall problem may be needed to make *PatientsLikeMe* commercially viable and attract partner resources. Apparently, centralization and decentralization can co-exist, albeit on different levels.

The *motivations* to participate in *PatientsLikeMe* span broad spectra, and differ between different stakeholders. For patients and their next of kin, the core motivation typically revolves around their illnesses and how to improve their health. They primarily want to contribute to problem solving that they or their relatives can benefit from directly, but they also contribute to more long-term research from which many people can gain. These mechanisms are further enhanced by social media features such as likes and starts, designed to further encourage users to contribute. For scientists, motivation to take part in *PatientsLikeMe* is to get access to patient-centric data and to mobilize and elicit patients in research projects for multiple contributions. For the *PatientsLikeMe* team there is also commercial motivation. Despite being motivated by partly different aspects, all stakeholders' motivation aligns to a higher, civic cause of providing better treatments and improved health care, guided by the belief in patient-centric research, were the patients' experiences are highly valued.

However, it is only the end-user who provides data, and that is why the end-user is particularly important in open and distributed innovation efforts. In user driven innovation (von Hippel, 2006), motivation is associated with personal needs to adapt or add functionality to a product. In crowdsourcing and innovation contests there is often an element of extrinsic reward, such as money, a prize or other benefits. In open source, a wide set of motivations to contribute has been reported such as ideological, gain from reputation, fun and economic (von Krogh *et al*., 2013).

Legitimacy seems to be an important motivator in many forms of open and distributed innovation, not the least so in *PatientsLikeMe*. No one wants to share sensitive health data without strong conviction that privacy is protected and that it is for a good cause. Contributing with a piece of code to an open source project, a design idea for cars, or an innovative application is different from sharing information about painful experiences and worries for one's health. While motivational aspects of open source software is well researched (von Krogh *et al*., 2012), the kind of motivations that are central to *PatientsLikeMe* has rarely been addressed in research and provides an interesting avenue for future research.

In sum, there are both intrinsic and extrinsic motivation for stakeholders to participate and try to reach the long-term goal of improved patient-centered health care. By exploiting regular social media features, end-user contributions, which are vital in open and distributed innovation, are actively promoted

Regarding *organization and governance*, *PatientsLikeMe* is a professional, for-profit organization. A management team makes strategic decisions, research teams coordinate research projects, and patient experience teams act as facilitators for the community. While the patient community appears to have a good portion of self-organizing, this organizing must take place within the overall schema provide by *PatientsLikeMe*. This means that *PatientsLikeMe* is firm-centric when it comes to governance. However, it is not uncommon that open source projects implement forms of diversified roles in terms of small core development teams, separated mailing

lists and forums for different groups, and restricted access to members, in order to achieve more efficient coordination mechanisms (Feller *et al*., 2008).

One essential governance dimension in all open and distributed innovation is the degree of proprietary/privacy versus openness. Closely linked to this is the intellectual property regime. When registering as member to *PatientsLikeMe* one signs a terms of use agreement, giving *PatientsLikeMe* right to trade the shared data on their terms. However, openness is only valid within the closed community, and the aggregated data is mainly open to paying partners. Thus, the shared data could not be claimed to be a commons. The business model for *PatientsLikeMe* requires such an arrangement. Data is the main asset here, but the patient community is also an asset, as it gives fast access to potential participants in research studies and clinical trials. This also relates back to question of *PatientsLikeMe's* legitimacy and patient's motivation to share data.

In sum, although all data is provided by the patients, they have agreed to let *PatientsLikeMe* use the aggregated data commercially. While this aggregated data is shared with other stakeholders, it is not shared openly and cannot be considered as commons - *PatientsLikeMe* maintains exclusive ownership. There is thus no separation of governance and property in this case.

PatientsLikeMe's use of social networking features

The central task for the *PatientsLikeMe* web site is to accelerate research and improve treatments for chronic diseases by harnessing the experiences from actual patients all over the world. This overarching and long-term goal can only be achieved if patients also receive tangible, short-term benefits. *PatientsLikeMe* realized that this required features that allowed members to link up in communities, express their stories, make these stories publicly displayable and store these testimonies for future reference. These are all activities afforded by social media in form of association, editability, visibility and persistence - using the terminology of Treem and Leonardi (2012). These affordances allow member patients and their families to conceptualize both problems and solutions, albeit within the frames defined by the structure of the site and the overall agenda set by *PatientsLikeMe*.

PatientsLikeMe exploits several SNS features to motivate people to contribute. One such feature is the rich user profile. A profile may contain the usual demographics, photos and images, but also more domain specific information such as medical journals, evaluations and biometrics. This caters for the members' self-expressional urges. However, unlike users of more leisure-oriented SNS, *PatientsLikeMe* members have a thirst primarily for disease related knowledge that can be obtained from other patients with similar conditions. It is therefore important that people not only become members - it is also vital that as many as possible actively contribute.

The perhaps most obvious feature to facilitate contributions is the status update function that allows patients to directly share what is on their minds. However, closely linked to this are features such as comment, like and share, which offer peers the ability to align with the status updater by showing support for a particular concern. Many likes for a particular issue shows that this attracts the attention of many members and thus promotes the issue as a task to be prioritized. Feedback mechanisms are also known to have a positive effect on contributions, and likes and (positive) comments have shown to be a particularly important means to encourage newcomers to start contributing (Burke et al., 2009).

In addition, explicit feedback icons in forms of stars are awarded to contributing members and added to their profile as visible status tokens. The *PatientsLikeMe* site offers search features that allow users to search explicitly for information provided by "starred" members. SNS features like these allow contributing users to rise above the crowd and receive respect and gain followers, which provides social gratification.

PatientsLikeMe as a company has also a financial motivation to encourage patients to enroll since more members generates more data, which in turn is aggregated and sold to partners. Although *PatientsLikeMe* started with, and still has, a strong civic and empathic cause, it is also a for-profit company. An SNS can also be understood as an information infrastructure, and as such, a large user base offers more value to each member and creates a network effect that is self-reinforcing, as it is attracting more users that creates even more value (Hanseth, 2000). This added individual value transfers also to the company as it increases its attractiveness as a business partner.

PatientsLikeMe membership is free (of charge) but not free (to everyone). Only people with chronic diseases (or care-takers or family members) are accepted. The fact that *PatientsLikeMe* offers a gated community actually not only promotes sharing but is essentially a prerequisite for sharing. *PatientsLikeMe* users display their disease history and reveal their medical records knowing that only those who are considered 'authorized' are allowed access. New presumptive users are screened before given member status and this way of organizing and governing provides a trusted environment where patients and their friends and families feel safe to expose themselves. This makes *PatientsLikeMe* somewhat different from traditional SNS.

It is common for SNS to allow users to create subgroups or sub-communities within the larger site. *PatientsLikeMe* offers a variety of disease-specific sub-communities but these groups are created by the *PatientsLikeMe* organization and not by the users themselves. This governance policy stems from the central task of providing data for research. Thus, although there are over 2400 conditions registered in *PatientsLikeMe*, only diseases for which there is ongoing research are of interest, and *PatientsLikeMe* makes those decisions.

In sum, where regular social media sites such as Facebook impose no overall purpose or agenda on their users, *PatientsLikeMe's* management team has a particular agenda that governs all use and restricts certain aspects of the SNS features. *PatientsLikeMe* is therefore not a traditional "general purpose" SNS. The *PatientsLikeMe* site does contain many SNS features and it is obvious that both site owners and end-users benefit from the affordances of the SNS.

Ways in which CBPP and SNS features interplay

Above, we have discussed *PatientsLikeMe* from both a CBPP perspective and from an SNS standpoint. The purpose of this paper, however, has been to study *PatientsLikeMe* in order to understand better in what ways peer production and social networking features interplay. We therefore now broaden the analysis and discuss how where and how specific SNS features align positively with the pillars of commons based peer production, summarized in table 3 below.

Table 3 Pairing SNS features with CBPP pillars

SNS features	*Pillars of Commons-Based Peer Production*		
	Decentralization	*Motivation*	*Organization*
Profiles Status updating	Users write in the status field what is important to *them*.	Being able to see what and how friends post motivates users to add content themselves.	
Adding/revising/deleting own content	By adding content, each user can influence the direction the SNS site is taking. A task or problem can be reformulated by the contributor as his/her knowledge increases.	Knowing that items can later be edited, corrected or removed lowers the barriers for posting.	
Subscribing Follow		To have 'followers' is known to be a highly motivating factor.	Subscribing to, linking to or following other users form a user-centric network.
Comment Sharing Liking	Others can endorse specific tasks by liking, sharing or adding smileys to certain status updates. Liking or voting for a user-added suggestion helps promote a bottom-up approach to task conceptualization.	Liking or voting for a user-added suggestion also encourages the contributor to continue.	Users who share or like a status update form an implicit, self-organized sub- group.
Social gratification Voting	Voting allows for bottom-up decision making.	Obtaining official promotion insignia such as 'stars' gives recognition and status.	Allowing users to vote for or like things gives them the power to state what is important and what is not.

Focusing first on the CBPP pillars, we notice that it is primarily *Decentralized conception and/or execution of problems and/or solutions* and *Ability to motivate people to contribute* that benefit from SNS features. Motivation is enhanced by many different SNS features whereas decentralization is supported by fewer features but in in more ways. Organization, i.e., *Separation of governance from property*, is also supported but not quite as pronounced. The finding that task

decentralization is supported is fully in line with previous academic findings suggesting that social media seem to align best with a decentralized approach to information management (Stenmark & Zaffar, 2014). The affordances of social media – association, editability, visibility and persistence (Treem & Leonardi, 2012) – all promote a bottom-up perspective that empowers the individual. This may also explain why there are fewer features supporting governance issues. The human needs for social ties are since long well established, as are the benefits that people derive from these ties (cf. Eisenberger & Cole, 2012). Since social networking sites exploit such social ties, it seems plausible that this technology motivates people to engage, and this motivation is thereafter further propelled in self-reinforcing loops. The more users who join, the stronger the motivational effect will be.

When turning to the SNS features, we note that the class of features that seem to be most useful from a CBPP perspective is *Comment, Sharing & Liking*, along with *Social gratification and Voting*. Although not all SNS features explicitly facilitates the separation of governance and property, this is implicitly supported through the strong decentralizing affordances of the technology. Because of these features, strong governance is difficult to achieve. Obviously, the SNS owners can exercise certain amount of governance by mandating what not to do by having policies regarding content and tonality, and enforce such policies by deleting inappropriate content and banning disobedient users. However, the SNS owner can typically not control what the users can do; what topics they engage in, or what ideas they express.

Stenmark and Zaffar (2014) argue that governance in SNS should not follow the command-and-control approach traditionally used in information management, but encourage a bottom-up approach. SNS do easily allow for the separation of governance and property and we therefore argue that SNS features do actually support also the third pillar of CBPP - if used in an informed way.

Conclusions

To answer our research question, we find that peer production and social networking interplay best when it comes to the decentralized conception and execution of problems and solutions *and* when it comes to the ability to motivate and spur participation and contribution - especially from end-users. It is in particular the possibilities to share, comment, and link and the social gratification features that align positively with peer production.

Further, from a CBPP perspective, our data shows that centralization and decentralization can co-exist on different levels. The case also shows that although motivation takes different forms for different stakeholders, there is strong and aligned focus on health innovation. The users' participation is enhanced through social media features. Finally, our results show that there is no separation of governance and property in this case, but a rather firm-centric governance model. Our case does thus meet some but not all of the criteria for commons based peer production. Yet, using Benkler's theory regarding CBPP has turned out to be a useful analytic tool when trying to understand the case.

Our data describes a hybrid form of commons based peer production that fulfills only partially the criteria suggested by Benkler. It would be closer to what Benkler calls firm hosted CBPP, but has at the same time civic goal, and one can discuss whether or not the outcome of the R&D (e.g., new and innovative treatments) should be considered a commons. Looking deeper into a case like this contributes to the knowledge of open and distributed innovation in general, and to commons-based peer production in particular. The combination of peer-production and social

networking features has a potential to increase efficiency and transparency in other important areas of societal development, where market or state initiatives are not enough, and deserves more research.

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