

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.