Chapter 52
Participatory Online Platforms and the Construction of Citizen Autonomy in Health Issues

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ABSTRACT
The goal of the present study is mapping the nature of possible contributions of participatory online platforms in citizen actions that may contribute in the fight against cancer and its associated consequences. The research is based on the analysis of online solidarity networks, namely the ones residing on Facebook and the blogosphere, that citizens have been gradually resorting to. The research is also based on the development of newer and more efficient solutions that provide the individual (directly or indirectly affected by issues of oncology) with the means to overcome feelings of impotence and fatality. In this chapter, the authors summarize the processes of usage of these decentralized, freer participatory platforms by citizens and institutions, while attempting to unravel existing hype and stigma; the authors also provide a first survey of the importance and the role of institutions in this kind of endeavor; lastly, they present a prototype, developed in the context of the present study that is specifically dedicated to addressing oncology through social media.

INTRODUCTION
This project aims to implement a platform of understanding to the contexts of contemporary media network concerning the problem of cancer. This study, focused on emerging information management systems, both horizontal and decentralized, such as social networks or blogs, involves the presentation of a synthesis of the first stage of research prior to the current one.

The study began by the end of the year 2005 and did not arise from a request from an organization.
Participatory Online Platforms and the Construction of Citizen Autonomy in Health Issues

or institution, but rather on a private enterprise after the awareness of a need. In the Portuguese context, information that was on the Internet related with pediatric oncology, in sites that give citizens guarantees regarding issues such as reliability and safety was sparse and insufficient that year – there was a wide gap on national Websites targeted to parents in particular and to the public in general. As a consequence people easily gave up using them to search for information. Furthermore, this inadequacy meant that the health care professionals would not encourage this consultation on the Web.

The purpose of this study was to offer a cheaper and faster way, such as the Internet, that would allow the publication of much more information, more specialized and updated (Martins, 2007).

The site www.oncologiapediatrica.org was released in March 2007, and the tendency was always of growth. In 2007 the average number of visits per day was 91.9, rising in 2008 to 229.1, in 2009 to 274.8 and in 2010 to 303.9 visits.

As we shall see ahead, these positive results finally demonstrate that the initial strategy to develop a hierarchical pyramid structure site should be reevaluated and that the difficulties identified and analyzed during the investigation reflected in the dynamics of the site over time that has elapsed.

Since this is a sensitive and complex topic where the goal was to safeguard the safety and credibility of the contents to Web users, it was thought that a centralized monitoring system would be the best. The consensus on this option was total, by all entities and individuals interviewed. However, it should be noted that in 2006, both platforms 2.0 and social networks, based on a more horizontal logic existed already, but their prominence and popularity only began to show in Portugal as of the mid-2008.

Although one of the major goals is to create a cohesive space, in order to contribute to the development of a networking between the several institutions, healthcare professionals and citizens – i.e., an horizontal relationship – the major concern of this study focused on the safety and credibility of the contents published: to allow any citizen to publish freely an informative content was a risk that was necessary to eliminate.

However, during the fieldwork, we realized it was very difficult to bring together clinical contents to the site, due mainly to the limited availability of healthcare professionals in this area. The same difficulties were experienced in the numerous attempts to create an organized and solid human structure platform to work on, within each institution and also as an attempt to develop a joint, collaborative, and networking collaboration among the several institutions. This scenario led to a relatively pessimistic intuition concerning the future of this project, since it predicted a small contribution from healthcare professionals.

The Website’s success is due mainly to the several forums around the site. Although these forums are monitored – the contents are only published after prior approval – they work as open spaces used by visitors to write messages: news, testimonials, questions, or concerns. These contents, written by several people, triggered unexpected dynamics in the site.

The need for awareness to participate in the project decreased. The many voluntary contributions received from citizens led gradually to diminish the necessity to promote the site. Another important fact was the community that spontaneously emerged and is still growing, mainly through these forums. Because of their dynamic and mobilizing capacity, several of these members developed closer ties with the team responsible for the project, becoming themselves important and active voices in the management of the site.

These results, as well as the growing popularity and power of Web 2.0 platforms, require a reflection on what system is more effective in mobilizing citizens and institutions, in actions