



# Improving Patient Involvement in the Drug Development Process: Case Study of Potential Applications from an Online Peer Support Network

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## ABSTRACT

To date, social media has been used predominantly by the pharmaceutical industry to market products and to gather feedback and comments on products from consumers, a process termed *social listening*. However, social media has only been used cautiously in the drug development cycle, mainly because of regulations, restrictions on engagement with patients, or a lack of guidelines for social media use from regulatory bodies. Despite this cautious approach, there is a clear drive, from both the industry and consumers, for increased patient participation in various stages of the drug development process. The authors use the example of HealthUnlocked, one of the world's largest health networks, to illustrate the potential applications of online health communities as a means of increasing patient involvement at various stages of the drug development process. Having identified the willingness of the user population to be involved in research, numerous ways to engage users on the platform have been identified and explored. This commentary describes some of these approaches and reports how online health networks that encourage people to share their experiences in managing their health can, in turn, enable rapid patient engagement for clinical research within the constraints of industry regulation. (*Clin Ther.* 2017;39:2181–2188) © 2017 Elsevier HS Journals, Inc. All rights reserved.

**Key words:** online peer support network, patient centricity, patient voice, social media, user generated content.

## INTRODUCTION

### The Phenomenon of Social Media

Social media facilitates the sharing of information, experiences, and ideas among groups of people across the world with access to an internet connection. In an

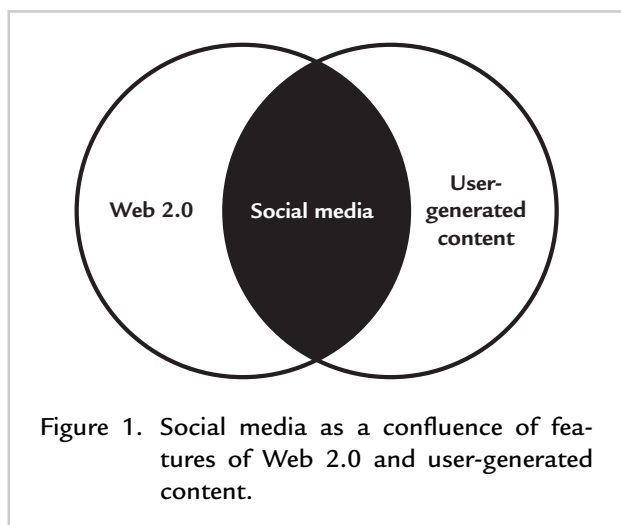
analysis of global digital users performed in 2017,<sup>1,2</sup> >3.77 billion people were found to use the internet, which indicates a 50% penetration (ie, the number of people using the internet as a percentage of total global population). Of this, 2.8 billion people are determined to be active social media users. These rates were similar to those reported in the Pew Research Center's Spring 2015 Global Attitudes survey.<sup>3</sup> The annual growth has followed an exponential trend in the past year, with a 21% increase seen in social media users from 2016.<sup>1</sup>

### The Functional Evolution of the Internet

In addition to its user growth, the internet has come a long way functionally since its inception as a worldwide bulletin board system for sharing of messages, software, data, and news. It evolved to include company web pages and e-commerce during the explosive period of corporate growth between 1995 and 2001.<sup>4</sup> The recent evolution into an internet dominated by social media can be seen as a return to its initial utility as a peer-to-peer medium for exchange of information and news. Hence, social media has taken the internet full-circle back to a peer-driven system, but one that is ubiquitous and influential. Notably, social media is different from Web 2.0 (a platform where users continuously modify content in a collaborative manner) and user-generated content (all forms of media content created by and available to users); in fact, social media builds on Web 2.0 and allows creation of user-generated content (Figure 1). The key elements of this computer-mediated technology are the social presence (which

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is linked directly to social influence) and the richness of content (which determines the effectiveness of the communication).

The pervasiveness and utility of social media in health and well-being are no exception. With high levels of consumption and sustained engagement, social media opens up venues for introducing online interventions that affect health behaviors.<sup>5</sup> The popularity of Facebook has facilitated many health behavior research studies in different populations with varying demographic characteristics and on a wide range of health behaviors, including weight loss,<sup>6-10</sup> physical activity,<sup>11-16</sup> and smoking cessation.<sup>15</sup> This medium allows for research to be conducted in private groups via polls or through apps on the platform. Twitter has also become a popular source of improving social engagement and has enabled the analysis of text within this medium to examine population-level health needs and behaviors.<sup>5,17,18</sup> Beyond the broad social networks, online patient communities and networks for health have allowed users to share information in dedicated, disease-focused networks, allowing them to log their experiences regarding their health. Furthermore, the anonymity and security offered by a peer environment have emboldened more people to be open about their struggles and challenges in managing their health.

### Slower Uptake in Drug Development Research

In the first part of this decade, social media played a largely commercial role in targeted areas of the drug

development cycle. In 2014, a White Paper<sup>19</sup> published by Tufts Center for the Study of Drug Development discussed and reviewed the use of social and digital media in clinical research. It noted that social media was used largely to market products and to gather feedback from consumers, with very few examples that supported clinical research. The same White Paper provided recommendations for patient recruitment and retention, development planning and study design, and adverse event reporting through communities on social media. In addition, patient-reported content has been used in the pharmacovigilance step of the drug development cycle for detection, assessment, understanding, and prevention of adverse events related to drugs, but there is a trend of underreporting these adverse events in postmarketing surveillance systems.<sup>20</sup>

This article takes a view, 3 years on, of how social media and peer networks have evolved to play a much deeper role in innovation and clinical research in industry and how the use of an online health platform's underlying semantic data structuring and artificial intelligence in its early stage is changing the opportunity for patients to participate in research and development of new therapies.

### The Next Wave of Patient Involvement

We use HealthUnlocked.com (HU), a health social network with >40 million global visitors from August 2016 to August 2017, to provide a range of examples to illustrate how direct patient engagement in drug development through social media has evolved since 2014. These include examples include the following: involving patients in designing clinical trials, recruiting and screening patients into trials, running longitudinal research studies online, planning new drugs based on patient need, and surveilling the use of drugs and adverse events following launch into the market. These areas of patient involvement highlight how the role of the patient in drug development is changing significantly from the very early stages of exploring a new molecule through clinical trials and then the eventual launch of a new compound.

Methods developed to improve patient involvement in the drug development cycle included obtaining informed consent from all participants as standard protocol. The user was presented with a consent form that outlined the purpose of the research, research

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