

## Perceived healthcare provider reactions to patient and caregiver use of online health communities<sup>☆</sup>



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### ABSTRACT

**Objective:** Many Internet users seek health information through online health communities (OHCs) and other social media. Yet few studies assess how individuals use peer-generated health information, and many healthcare providers (HCPs) believe OHCs interfere with patient–provider relationships. This study explored how individuals use OHC content in clinical discussions and how HCPs react to it.

**Methods:** We conducted in-person and virtual focus groups with patients/caregivers who visited OHCs ( $n = 89$ ). A trained moderator asked about reasons for membership, sharing OHC content with providers, HCP reactions, and preferred roles for HCPs. Two researchers independently coded verbatim transcripts (NVivo 9.2) and conducted thematic response analysis.

**Results:** Participants described OHCs as supplementing information from HCPs, whom they perceived as too busy for detailed discussions. Almost all participants shared OHC content with HCPs, although only half cited OHCs as the source. Most HCPs reacted negatively to OHC content, making participants feel disempowered. Despite these reactions, participants continued to use OHCs, and most desired HCP feedback on the accuracy of OHC content.

**Conclusions:** Individuals do not use OHCs to circumvent HCPs but instead to gather more in-depth information.

**Practice implications:** HCPs should discuss OHC content with patients to help them avoid misinformation and make more informed decisions.

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## 1. Introduction

Research has demonstrated that the Internet is an increasingly popular source of health information for U.S. adults, with 70–80% of Internet users seeking information online about symptoms, treatments, medications, and medical costs for themselves or loved ones [1–4]. Individuals report that such information improves their understanding of health issues, influences their treatment decisions, and leads them to share new information with their healthcare providers (HCPs) [5–8]. Although search engines and

medical Websites are the most popular starting points for online health information, approximately 25% of individuals also turn to social media sites [1,3,9].

Online health communities (OHCs)—Internet-based discussion forums where individuals converse with one another about health topics—are the most robust social media sources for peer-generated health information [9–12]. Almost 20% of Internet users have participated in OHCs, and individuals with chronic conditions or who serve as caregivers are even more likely to visit OHCs [3]. Although treatments and medications are the most common OHC discussion topics, individuals also share experiences related to health insurance, HCP satisfaction, and self-care activities [9,13].

Despite the popularity of online health information seeking, there is conflicting evidence on how it affects patient–provider relationships. On one hand, some studies suggest that patients frequently share online information with HCPs and that HCPs view online health seekers positively, believing that these patients are more informed and engaged and that online information seeking

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has more benefits than harms [14–16]. Conversely, other research suggests that patients are sharing online information with HCPs less often and that most providers have negative attitudes toward online research [5,17,18]. These latter studies indicate that HCPs are often unaware of their patients' online activities, perceive patients who seek online information as misinformed and anxious, find it challenging to evaluate the credibility of online content, and fear that patients may act on online recommendations without first consulting their doctor [5,14,16–19].

The evidence on how social media affects patient–provider relationships is even more limited. Very few studies have examined how individuals use peer-generated health information or how HCPs perceive this content, and the research in this area is limited by small sample sizes, poor response rates, and a lack of detail [20–22]. The existing research suggests that half of HCPs believe social media interferes with patient–provider communication and that many providers are concerned that OHCs spread misinformation or are forums for complaining about providers [20,21].

Given the popularity of seeking health information through social media and the limited evidence on how OHCs affect patient–provider relationships, the purpose of our study was to explore how patients and caregivers use peer-generated health information from OHCs in clinical discussions and how they perceive HCPs as reacting to this information. (The study also examined other aspects of OHC membership—such as privacy, credibility, and how OHCs influence individuals' health decisions—and these findings are reported in a separate paper.) Specifically, we examined four research questions:

- (1) *OHC Membership*. To what extent do interactions with HCPs affect patient/caregiver participation in OHCs?
- (2) *Sharing OHC Content*. How often do patients/caregivers share OHC content with providers and how do they frame this information?
- (3) *Provider Reactions*. How do HCPs react to OHC content and how do patients/caregivers interpret these reactions?
- (4) *Preferred Provider Role*. What role do patients/caregivers want HCPs to play in their health decisions given the increasing availability of peer-generated health information?

## 2. Methods

We conducted ten in-person and virtual focus groups with OHC members to examine these research questions (Fig. 1). Study participants included general OHC users (Groups 1–3); active/heavy OHC users (Groups 4–5); passive/light OHC users (Groups 6–7); OHC users recently diagnosed with fibromyalgia (Group 8); OHC users who recently made a major treatment decision related to clinical depression (Group 9); and users who all participated in the same multiple sclerosis OHC (Group 10). The first seven groups were conducted in person. The remaining three groups were conducted virtually on a live chat platform.

Focus groups are ideal for rapidly examining individuals' perceptions and behaviors in depth, which would be difficult using quantitative methods [23]. Although virtual focus groups are a relatively new methodology, some studies have documented their advantages and the comparability of in-person and virtual focus group data [24–28].

We selected this ten-group design to reach a geographically diverse sample of OHC members, including individuals who may not have been able to participate in person, and to examine specific sub-groups (e.g., passive users). We held the groups from September to December 2011 in Washington, DC; Raleigh, NC; Chicago, IL; and online. The study was approved by ethics boards at RTI International and the U.S. Food and Drug Administration.

### 2.1. Eligibility criteria

Eligible individuals had to be ages 18 or older, speak English, and have read or posted content in at least one active OHC for themselves (patients) or a child/parent (caregivers) within the last month. We included caregivers because half of online health research is conducted for someone else [1]. We visited OHC URLs provided by potential participants to confirm that site content was mostly or exclusively member-generated, posted within the last week, and focused on a medical condition rather than general health and wellness. We excluded individuals who belonged to ineligible or inactive communities, who participated in OHCs as part of their job, and who worked in the healthcare or pharmaceutical industries.

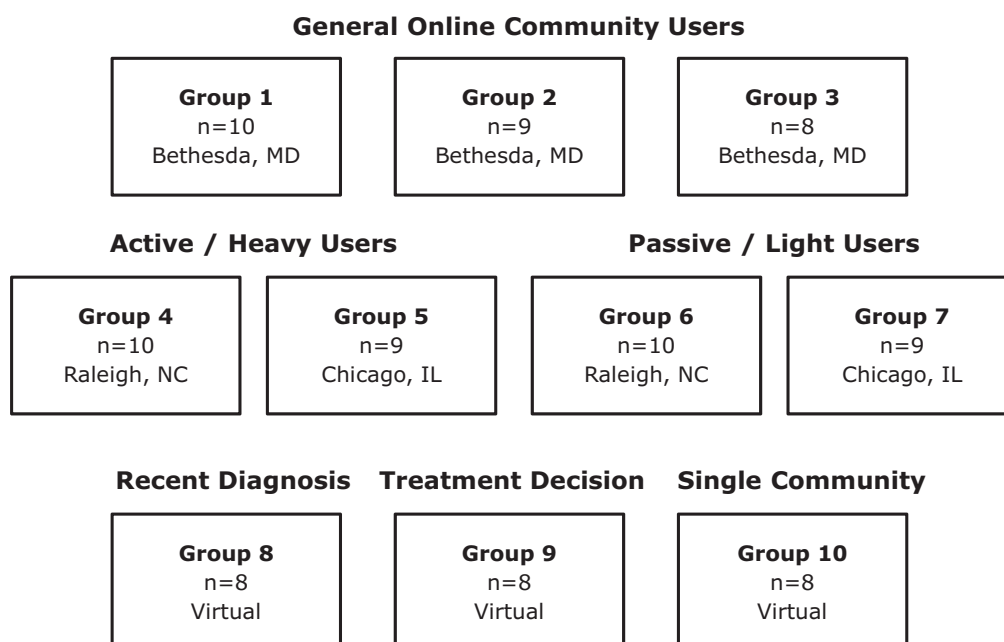


Fig. 1. Focus group populations, locations, and sample sizes.

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