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# Ethical Challenges in Online Health Community Research

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**Abstract**

Online communities organized around chronic illness are a valuable resource for patients because of the difficulty of finding local, offline resources. Researchers also benefit from such online communities because they provide insights into how people cope with illness and behave in groups online. In response to a growing body of work that uses data collected from online communities, researchers have suggested guidelines for conducting this research, examining what constitutes public and private spaces online and using this knowledge to improve ethical online community research. However, there are a number of ethical issues specific to online health-related communities that are not adequately addressed, since community members are often dependent on the information they receive from online communities and post sensitive medical and personal information with the intent of helping others. We recommend that researchers examine the risks of analyzing and publishing information from these communities, and consider ways to empower group members and provide them with opportunities to contribute to their community.

**Keywords**

Online communities, online health communities, health information, research ethics, chronic illness

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H5.3. Information Interfaces and Presentation: Group and Organization Interfaces---Asynchronous interaction, Computer-supported cooperative work, Web-based interaction

### **Introduction**

People are increasingly turning to online communities to find health information. Between 2001 and 2003, the percentage of adult Internet users reporting they participated in a health-related online community increased from 36% to 54% [9]. Though people visit these sites with a variety of different goals, those who participate in online communities can benefit from the opportunity to learn from and interact with other community members [3, 6].

For people with chronic conditions, these online resources are particularly valuable. The implications of chronic illness often extend beyond a person's physical health, negatively impacting relationships with friends and family and posing a serious financial burden [10]. Furthermore, it can be difficult for chronically ill patients to find local resources, such as medical specialists and support groups, to help them cope with and treat their illness. As a result, online communities serve two vital functions: they provide a place for patients to find medical information, and a supportive environment in which people can connect with others who have had similar experiences [7].

In this paper, we draw from existing literature, in addition to our experiences interacting with online communities and interviewing people with chronic illness, to explore the ethical issues inherent in working with information collected from online communities.

### **Lyme Forums**

As part of an investigation of chronic illness and Internet use, our research group reached out to online communities focused around Lyme disease. It was our goal to recruit community members to participate in surveys and interviews about their online health resources use.

Though we had IRB approval for the work, we faced resistance from some group moderators. Recruitment posts were met with a flurry of warnings, advocating against participation. These "gatekeepers" were concerned that we might take advantage of access to their site, and potentially harm community members through our research processes and resulting publications. Some gatekeepers wanted information, in advance, about what we would say about their group members. There were also requests to see our IRB documentation. It was only after clearly explaining our research interests, through a number of phone and email conversations with gatekeepers, that we were granted access as community members. While these moderators had valid and thoughtful concerns, we could not conduct valid scientific research if the outcomes were pre-ordained, and sharing the detailed goals of our study could influence its outcome.

Having established our motivations for studying the communities, we recruited over 150 participants, about a dozen of whom agreed to participate in a series of interviews. During these interviews, participants described their experiences looking for information online and offline and how this information impacted their lives at different stages of illness.

As described in Mankoff et al. [8], Internet resources played a significant role in how many of our

participants learned about Lyme disease and sought treatment. There is a great deal of controversy surrounding Lyme disease diagnosis and treatment [8], and the experiences relayed by our participants reflected the toll of this controversy. In keeping with the trends from the Pew Internet Research survey [9], a number of these participants reported that, frustrated by the medical help they had received, they turned to the Internet to try to identify the cause of their symptoms. Their searches eventually led them to forums where they read posts that helped them make connections to possible causes of their symptoms. Several of the participants spoke about having used these forums to compare their symptoms others' and to learn about treatment options. The forums also allowed them to forge new relationships with people with whom they could share their experiences.

### **Ethical Issues and Recommendations**

In addition to the services provided to users, an auxiliary benefit of online communities is that they provide researchers with information that would be difficult and time consuming to collect using other methods. However, the use of this information raises some ethical questions. What privacy expectations do users have when posting health related information? And, based on those expectations, what obligations do researchers have to protect contributors of information [2, 5]? Additionally, for researchers working with controversial topics, there are concerns about researchers remaining objective. Although there are no clear answers to these questions, some researchers have suggested possible solutions, such as assessing the perceived privacy level of a community, considering the harm publishing data may bring to the community, and obtaining informed consent for quotes [2, 4, 5].

In our own work, we struggled with publishing direct quotes from participants. In one case, we wished to quote a public comment on a public blog post. A web search could be used to identify the author. Because this was publicly observable behavior, no consent form had been signed. Less public data, such as support group posts, is often also searchable. Though the process of obtaining IRB approval asks researchers to take measures to ensure that their data cannot be linked to individual participants, these regulations seem ill equipped to anticipate research work in which some of the data collected is publicly searchable. Additionally, for communities that are less open, there are lingering concerns about how researcher involvement might impact the community. In both cases, publishing sensitive information could be detrimental to the community, and, by extension, to the well being of the participants. We must therefore consider how researchers can use and collect this information without compromising the values of the community.

One option is to involve community members in the research process. We can minimize negative effects by informing members that research is being conducted, and working with them to address their concerns. Risks associated with this course of action include the possibility that participants will react negatively to this admission and that the group will be influenced, in some way, by this knowledge. Despite these risks, we feel that gathering input from members is in line with the overarching goals of these communities and of our work.

Another option is to examine how such research work can benefit the community and how researchers can engage participants through their involvement in the research. This technique, known more formally as

participatory action research, asks researchers to identify the issues that are important to stakeholders and to partner with community members to address these issues [1]. It is clear that active members have a vested interest in the continuing success of their community and the desire to reach out to others. Researchers can leverage these interests to provide tools that will empower community members and benefit the community as a whole.

### Conclusion

Online communities for sharing health information provide an important resource for patients in all fields of medicine, especially those suffering from chronic illness. While the medical community's primary responsibility is to provide effective cures to known diseases, there is an equally important ethical imperative to provide support to individuals for whom diagnosis is challenging, an area where HCI research can contribute greatly. Clearly, working to protect community members when conducting this type of research is a significant challenge. The information we have gathered from our work with patients with Lyme disease indicates that current guidelines do not fully address the concerns held by community members, nor do they provide sufficient protections for these members. As a result, we believe that the potential risks for participants and options for addressing those concerns warrant further discussion by the research community.

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