# Conducting Research in Online Communities

**Year**

2006

**Description**

When a sociologist and his graduate student are doing research on an online community, they debate whether they need informed consent from community members and if they should announce their intentions to study interactions online to participants in the forum.

**Body**

## Part 1

Dr. John McIntosh is a sociologist who examines the online behavior of members of virtual communities on the Internet. Roger Higgins is his graduate student research assistant. Dr. McIntosh intends to seek IRB approval for a new study he plans to conduct during the next year. This ethnographic study will evaluate how members of an Internet support group for a chronic illness establish, as well as learn, new formal and informal social norms for participation within that group. Dr. McIntosh and Roger will use social network analysis techniques to examine online messages posted by members of this virtual community in order to better understand the interaction patterns of its members.

Roger has identified a potential virtual support group to serve as the focus of their study. Known as “Narcolepsy Friends and Families” or NFF, it addresses medical issues associated with the neurological disorder known as narcolepsy, as well as the social stigma that can accompany it. Narcoleptics experience unexpected and uncontrollable episodes of deep sleep and related symptoms. Members of the NFF community often are narcoleptics themselves, or have a close friend or relative with this illness.

Two levels of access to the NFF online community are available: registered members and unregistered guests. NFF registration is open to anyone who wishes to become a member; there are no explicit prerequisites. Registered members of NFF log in to the community web site via a username to post messages, as well as to edit or delete their own prior messages. Additional privileges for registered members include the ability to create a profile that reveals their real name and other identifying information if desired, or simply to use their username as a pseudonym instead. There are approximately 200 registered participants in the community, although only about 80 members post messages regularly.

As with many online support groups, NFF turnover is high since many individual members have joined and then left the community during its five-year history. To facilitate continuity, each message posted on the group’s web site is archived by date as well as topic, and is publicly accessible to unregistered guests without login. Unregistered guests also can conduct keyword searches to locate specific messages, such as information about particular treatment options.

Dr. McIntosh is concerned that if the research team announces its intent to study the NFF virtual community, then members will be aware that their messages are being monitored and may act differently as a result, possibly affecting their research results. He proposes that Roger subscribe to NFF’s online community forum and “lurk” as an invisible presence to gather research data. Roger is uncomfortable with this idea because he thinks that NFF group members should be aware that they are the subjects of an ongoing research study, particularly since their discussions often involve sensitive personal topics. Dr. McIntosh points out that the NFF group does not limit its membership. Therefore, he considers the online community to be a public space so that informed consent is not required.

### Questions

1. Is informed consent necessary in this situation, or could this research study qualify for an exemption under federal research guidelines? What might be reasons Dr. McIntosh and Roger would consider seeking IRB approval for their study even if it qualifies as exempt?
2. Since some NFF participants are known only by username and their profile does not provide additional personal information, how should the researchers address the concern that members of vulnerable populations (such as children or mentally challenged individuals) might become involved in the study?

## Part 2

As an alternative, Dr. McIntosh suggests that Roger capture the NFF community's public messages posted on its web site during the previous year and use them as research data instead. To determine the feasibility of this approach, Roger contacts Wayne, the NFF forum's moderator, and asks whether it is possible to download a year's worth of messages in bulk format from the web server where they are stored. However, Wayne declines to help him unless he seeks permission from the entire NFF support group first. Wayne acknowledges that archived NFF postings are public, but contends that participants did not expect their messages to be used for research purposes at the time they originally were posted. He adds that most participants are unaware that their postings are publicly available, and view their messages to other members as private communications within the NFF group environment.

### Questions

3. When collecting data, what are the researchers' responsibilities with respect to the participants in their study?
    a. Should Roger and Dr. McIntosh gather data by lurking in the NFF community unannounced? Why or why not?
    b. Should the researchers participate in online conversations as registered members, but not reveal their role as researchers? Why or why not?
    c. Should they request permission from the NFF group to download archived

    postings for retrospective research purposes? Why or why not?
    d. Should the researchers join the NFF support group and announce their plans, perhaps jeopardizing the integrity of their study? Why or why not?
    e. What might be more preferable alternatives?
4. To what extent should NFF members’ personal expectations of privacy in the online context influence Dr. McIntosh’s and Roger’s options for ethical research practices?

# Part 3

Dr. McIntosh and Roger decide to post a message to the NFF community to inform them that they would like to conduct research on NFF’s activities during the next year. In this message, they will offer to answer questions regarding the scope of their project, and ask for input in the study’s design. Roger and Dr. McIntosh will explain that NFF participants will be able to opt out at any time. The researchers also will promise that personal information will be kept confidential, and that individual identities will remain anonymous in published materials. They will assure NFF members that sensitive postings will not be quoted in detail in published reports without specific permission to do so.

However, Dr. McIntosh is concerned that it will be difficult to contact all 200 registered members of NFF since they are not required to provide an e-mail address in order to participate. In addition, many members may have changed e-mail addresses within the past five years, but not updated their profiles with their new addresses. In their initial posted message, Dr. McIntosh and Roger plan to suggest that current NFF support group members vote as to whether to participate. If a favorable consensus emerges, then Roger will post an informed consent form on the group’s website for willing members to download, complete, and submit via e-mail.

## Questions

5. Since revealing the true purpose of their research inquiry may change the nature of the NFF online environment and affect their results, should Dr. McIntosh and Roger provide a deceptive cover story and offer a subsequent debriefing to study participants? Why or why not?
6. Are Dr. McIntosh and Roger obligated to preserve the confidentiality and anonymity of member postings if those same messages also are available in

NFF’s publicly accessible archive on the Internet? Why or why not?

7. Should they include detailed quotes from anonymous participants if their real or pseudonymous identity subsequently can be revealed by searching the NFF archive for quoted material? Why or why not?
8. Does the researchers’ proposal for obtaining informed consent from NFF members as a group meet ethical standards for human subjects research? Why or why not?

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