

Research in online communities: An interactive workshop on privacy and human subjects research considerations

Questions for discussion

Belonging to an online community can be good for your health, especially if you have a disability, but do you know the implications for your privacy? What are your thoughts and opinions about health research being conducted within online communities? How can we balance protecting health information that people share with the realities of public spaces that are accessible with only a few clicks? Join Dr. Michelle Colder Carras, a health researcher specializing in video games, online communities, and health research for a frank discussion. Notes from the discussion will be used to inform designs and ethical protocols for research in online communities.

1. Human subjects research often considers online forum posts or video game worlds as public spaces and exempt from research protections. Do these online spaces differ from, say, a park or a town meeting? Should we even worry about protecting users' privacy?
2. Science has developed a strict code of research ethics, including ethical review, in response to past incidents of exploitation and harm to human research subjects (e.g., Nazi experimentation, using institutionalized and disabled children in research). However, this differs for different fields of research—computer scientists might not think of seeking ethical review, even when doing research on health, because their research designs often use aggregate data. The same applies to marketing firms and businesses—they collect and store data, then use it "to improve services" for individual users or all users, or even share or sell it with other businesses. Any type of research may even conduct experiments on users, for example changing the types of posts or chat they see, without their knowledge—yet for platforms, we agree to these when we use their services. Should one type of research or field of research have more protection than the other?
3. How should researchers communicate with online communities about conducting research – or should we? When should we communicate?
4. As a scientist and a person with a disability, I personally feel that it's ethically not right for me to conduct research without a deep level of interaction with and support from the online community. But it's hard to do that, because scientific projects are a big commitment. Communicating ideas clearly and accurately can also be a challenge. How can scientists work more closely and effectively with online communities to conduct research?
5. Platforms like Facebook and Twitter often use aggregated data for research, but many scientists who use text posts as data conduct qualitative research where bits of text become examples of the meaning they discover. We can leave off usernames and reword text so that it is not as easy to look up the user who wrote it, but what else can we do to obscure users' posts or virtual speech and protect their privacy?
6. What aspects of virtual communities need to be studied?
7. How do virtual communities improve health? What are some of the ways in which they might contribute to health problems?