

The ethics of recruiting study participants on social media

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(Medical Xpress)—In the recent issue of the *American Journal of Bioethics*, the target article addresses the ethics of finding participants for clinical trials on social media sites. The authors, from Harvard Law School and Harvard Medical School, analyzed the particular ethical issues that occur in the online setting compared to in-person recruitment and provide practical recommendations for investigators and Institutional Review Boards (IRBs).

"Recruitment to [clinical trials](#) is extremely challenging, raising distinctively practical and [ethical issues](#), and social media is beginning to show real promise as a recruitment tool, due largely to its ubiquity and use among just about every demographic," Professor Luke Gelinis of Harvard Law School told *Phys.org*. He says that there has been little serious reflection on the ethical and regulatory issues raised by recruitment using social media. He also thinks that recruiting via social media risks being under-utilized.

"Our working group wanted to address the ethical issues toward the end of providing some concrete guidance to IRBs and [investigators](#), which can hopefully facilitate the review and use of social media as a recruitment mechanism."

Today online communities provide virtual support groups for people with certain diseases and for their friends and family making virtual groups a good place to find potential research participants. Furthermore, social media allows researchers to find participants that have been traditionally hard-to-reach, such as those with rare diseases.

According to Gelinis, "One of the main takeaways from our article is

that recruiting online is in many ways similar to more traditional 'off-line' methods of recruitment. You can usually draw analogies between online and off-line scenarios—e.g., comparing approaching a social media support group for cancer to approaching an in-person hospital support group—that can help us get our bearings when evaluating social media recruitment."

In-person recruitment can be divided into two categories: passive and active. Passive recruitment might be posting a flyer in a doctor's office in hopes that a potential participant will contact them. This would be analogous to posting a banner ad on a medical website or an online patient support group.

Active recruitment, on the other hand, would involve emailing a particular patient in an online support group based on the person's online activity. This would be analogous to approaching a particular patient in a clinic based on the doctor's knowledge of his or her condition. With these two distinctions in mind, ethical guidelines can be laid out for online recruitment.

Where possible, the rules for active and passive recruitment offline, also apply to the online platform. Gelinas et al. suggest first identifying an analogous offline situation to the social media technique being proposed. In this way investigators and IRBs can identify the most pertinent ethical considerations in the offline situation and use them as a guide to the ethics of the online situation. Then, they can identify ways that the online version differs from the offline version.

In-person or offline ethical norms prioritize beneficence, respect for persons, and justice. These foundational norms can therefore be translated to the online world. However, the online platform is distinctive in that it provides more interconnectedness and embedded [personal information](#) than offline interactions do. Because of this, the

authors contend that every online interaction must address respecting the privacy and respecting the other interests of social media users. Additionally, they discuss the importance of investigator transparency in online interactions.

Respect for privacy can be a tricky thing when it comes to social media and other online platforms. For one, people may share personal information that, if they knew it would be used for research purposes, they may not share. Additionally, many people are unaware of online security risks and end up sharing information that is more easily accessible than they thought. Investigators are encouraged to seek permission to use personal information even if the information has technically been published online. Furthermore, investigators should not share personal information even if it has been shared online.

Transparency, which would fall under respect for persons, requires investigators to be up-front with who they are and the nature of their research online. Specifically when recruiting, investigators should be honest in describing the aims, details, risks, and benefits of their study. In many cases, investigators may need to contact the site moderator to obtain permission to recruit from their group. Additionally, investigators should not create fake online identities or pose as a participant of the group.

One issue that is specific to the online platform in regards to transparency is whether investigators are required to let people know that they are collecting data. Depending on the nature of the research study, investigators could reasonably obtain information just by "lurking" on the group page. The authors contend that the obligation for an investigator to disclose that he is collecting data is related to how public the particular social media group is. If the group is a closed-group in which only members can view comments, then this would likely mean the investigator should disclose that he is doing a study.

Another issue specific to online recruiting is tapping into someone else's network to find potential research participants. A participant's network will likely have people who have similar demographics, experiences, or qualities to the research participant. However tapping into the research participant's network risks disclosing the participant's eligibility for a particular clinical trial. Therefore, this must be done in such a way that protects the privacy of the participant.

Finally, there is a risk that people will discuss a clinical trial online. Unlike in-person trials where participants may not come in contact with each other, they possibly could interact online, especially if they are from the same support group or network. This may skew the results of the trial.

Clinical trials are an important part of medical research, but as many as 60% of clinical trials are delayed or cancelled because researchers cannot find enough research participants. Turning to [online](#) platforms increases the number of people that an investigator can reach, which in turn, results in more participants available for a study.

"While some IRBs have explicit policies in place for social media recruitment, many do not, and there is a sense, as in other areas, that the technology is outpacing the ethics," Gelinas says. "For IRBs who have the bandwidth, developing written policies and holding educational sessions on [social media](#) can be extremely helpful in getting members up to speed, and we hope that our work can be useful in this effort."

More information: Luke Gelinas et al. Using Social Media as a Research Recruitment Tool: Ethical Issues and Recommendations, *The American Journal of Bioethics* (2017). [DOI: 10.1080/15265161.2016.1276644](https://doi.org/10.1080/15265161.2016.1276644)

Abstract

The use of social media as a recruitment tool for research with humans is increasing, and likely to continue to grow. Despite this, to date there has been no specific regulatory guidance and there has been little in the bioethics literature to guide investigators and institutional review boards (IRBs) faced with navigating the ethical issues such use raises. We begin to fill this gap by first defending a nonexceptionalist methodology for assessing social media recruitment; second, examining respect for privacy and investigator transparency as key norms governing social media recruitment; and, finally, analyzing three relatively novel aspects of social media recruitment: (i) the ethical significance of compliance with website "terms of use"; (ii) the ethics of recruiting from the online networks of research participants; and (iii) the ethical implications of online communication from and between participants. Two checklists aimed at guiding investigators and IRBs through the ethical issues are included as appendices.

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