Using Social Media in Research: New Ethics for a New Meme?

Eric S. Swirsky,
University of Illinois at Chicago

Jinger G. Hoop, and
University of Illinois at Chicago

Susan Labott
University of Illinois at Chicago

The case vignettes presented here highlight ethical issues surrounding the use of social media in clinical research. To date, investigators and institutional review boards (IRBs) have had little in the way of specific guidance in this area. Written over 30 years ago, the Code of Federal Regulations for conducting human subjects research do not address social media (45 CFR 46). The U.S. Office for Human Research Protection, in its guidelines issued to address "significant challenges" presented by Internet research, recognized that "[e]thical conduct of Internet research…brings questions of scientific design into high relief…" (U.S. Department of Health and Human Services 2013).

The first case, regarding data collection via Facebook, brings up issues of consent, scientific merit, and confidentiality. First, the investigator wonders if the requirement for informed consent can be waived because viewing publicly accessible Facebook pages is akin to observing public behavior. This may not be the case. The personal use of social media has pre-existed its research application; therefore, users may feel that their Facebook page, even if publicly accessible, is still somewhat private and should not be subject to outside scrutiny by others, including researchers. Users may not fully appreciate the privacy risks involved in sharing information (described in more detail below), and they may therefore experience an online disinhibition effect (Suler 2004). Online disinhibition may encourage users to act and write in ways that they would find humiliating if observed by the general public or researchers.

Even if research of Facebook activities is considered to be an observation of public behavior within the scope of the Common Rule, it is not necessarily exempt from IRB review. There needs to be a determination of whether (1) the information is recorded in a manner that will allow subjects to be identified and (2) any disclosure of the subjects' Facebook posts "outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation" (45 C.F.R. § 46.101(b)(2) 2009). This protocol raises questions regarding how the digital information will be recorded, stored, anonymized, and secured because even if images are obscured to shield

Address Correspondence to Eric S. Swirsky, JD, MA, University of Illinois at Chicago, 1919 West Taylor Street, 250 AHSB (MC 530), Chicago, IL 60612, USA. eswir@uic.edu.

identities, investigators may unwittingly stumble upon more data than they had anticipated. Digital photos may contain additional metadata such as the date, time, precise geospatial information about where the photo was taken, and information from or about the device that was used to upload the file, including phone number and device identification. Finally, there is also a risk of liability because, for example, federal law makes it unlawful for minors to possess a handgun or ammunition absent an exemption (18 U.S.C. § 922(x)(2)).

The scientific merit of this study also comes into question because the online postings being studied may not be a valid source of data—due to the phenomenon of *trolling*, Internet slang for the practice of purposefully posting inflammatory messages. An Internet *troll* might make false or unwanted postings under the name of another user or might post untrue opinions simply to be provocative. Furthermore, even if authenticated, the views and attitudes of users of Facebook are not likely to be representative. The use of social media is not evenly distributed across demographics, as research has revealed a digital divide with regard to accessing and navigating health information on the Internet (Viswanath et al. 2013). Thus, finding that a high percentage of young males express positive attitudes regarding gun violence on Facebook may not provide investigators knowledge that is valid or generalizable.

In the second case, investigators wish to use social media to reach a research subject lost to follow-up, a possibility that was not considered during the consent process. Contacting the subject in this specific case appears to offer direct, possibly life-saving benefits to a subject who has expressed a desire to receive that information and may interpret the lack of contact as a sign that all is well. The investigators might plan to inform the IRB of a protocol deviation and send neutrally worded messages to the subject via social media along the lines of “Please contact X for important information as soon as possible.” Such a strategy appears to maximize benefits to the subject while minimizing the risks of loss of privacy.

In this and all cases involving contact between study personnel and subjects via social media, confidentiality issues must be carefully scrutinized, because information shared online contains and creates data that users and researchers may be unaware of. Simply because a user has established an online account does not mean that he or she truly understands the privacy implications. Social media platforms can have onerous terms of service; in some cases, they are contracts of adhesion, meaning that they can be changed unilaterally by the service providers and without notice. The terms of service may give service providers an ownership interest in the information posted, or they may prohibit the data from being used for research altogether. Google’s terms of service, for example, provide Google with a worldwide, perpetual, royalty-free license to content transmitted through their media (Google 2014). Thus, there is virtually no way to guarantee that privacy of online communication can be preserved as it is in the typical clinical research study.

In both cases presented here, ethical problems flourish in the chasm between the goals of clinical research and social media. The goal of social media providers is to commoditize data and maximize its monetary value; they are fixated upon the instrumental value of saleable information. Autonomy, beneficence, and respect for persons are secondary—if not irrelevant—to the bottom line. These are not the goals of the average clinical investigation

where researchers are guided to respect the intrinsic value of human subjects. Furthermore, clinical research is a highly regulated enterprise that is slow to change. Coupling it with a rapidly evolving, little-regulated industry has and will create ongoing problems as investigators, IRBs, and regulators scramble to try to stay informed of changes and create and update protocols and safeguards. Understanding these changes and analyzing their ethical impact requires not only ethicists, but also informaticians and information technology (IT) professionals.

Social media use is a natural evolution of the way people interact and communicate. It is the manifestation of a new meme (defined by Merriam-Webster as an idea, behavior, style, or usage that spreads from person to person within a culture), composed of individual units of cultural transmission, through which information is diffused in novel and sometimes unanticipated ways. The use of social media offers rich data and innovative methods of recruitment and retention—but also some unexpected ethical conundra because like all memes it can take on a life of its own, evolve, replicate, and influence the world of ideas. Thoughtful deliberation is required to keep on track ethically as we find new ways to use social media in healthcare research.

Acknowledgments

This manuscript was supported by the National Center for Advancing Translational Sciences **(UL1 TR000050)**. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

REFERENCES

Google. [accessed June 23, 2014] Google terms of service: your content in our services. 2014. Available at: http://www.google.com/intl/en/policies/terms/

Suler J. The online disinhibition effect. CyberPsychology and Behavior. 2004; 7(3):321–326. [PubMed: 15257832]

U.S. Code Â§ 922 - Unlawful acts_18 U.S.C. § 922(x)(2).

U.S. Department of Health and Human Services, Office for Human Research Protections. [accessed June 23, 2014] Considerations and Recommendations Concerning Internet Research and Human Subjects Research Regulations, with Revisions. Final document, approved at Secretary's Advisory Committee on Human Research Protections. 2013. Available at: http://www.hhs.gov/ohrp/sachrp/mtgings/2013%20March%20Mtg/internet_research.pdf

U.S. Code of Federal Regulations. Protection of Human Subjects, 45 C.F.R. § 46.101(b)(2). 2009.

Viswanath K, McCloud R, Minsky S, Puleo E, Kontos E, Bigman-Galimore C, Rudd R, Emmons KM. Internet use, browsing, and the urban poor: implications for cancer control. Journal of the National Cancer Institute Monographs. 2013; 47:199–205.