

## Lack of guidelines create ethical dilemmas in social network-based research

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With millions of adolescent users, social network sites (SNSs) are a rich data source for academic research studies. But ethical guidelines governing how researchers should obtain and use this data is seriously lacking, says Tufts University's R. Benjamin Shapiro, Ph.D., the McDonnell Family Professor in Engineering Education at Tufts University's School of Engineering, in an article published in the January 11 edition of *Science*.

"The use of social network sites for design research is accelerating but the academic research community and institutional review boards (IRBs) are way behind the trend when it comes to establishing adequate guidelines and best practices," says Shapiro.

A faculty member of Tufts' Center for Engineering Education and Outreach, Shapiro designs collaborative online <u>learning environments</u> for teenagers on <u>social networking sites</u> (SNSs).

Shapiro and co-author Pilar N. Ossorio, professor of law and <u>bioethics</u> at the University of Wisconsin Law School with a joint appointment at the School of Medicine and Public Health, highlight two key concerns in their paper titled "Regulation of Online Social Network Studies."

One significant question involves consent: At what age is it ethical to enroll young people in research related to SNSs without signed <u>parental</u> <u>consent</u>? Shapiro and Ossorio argue that current federal regulations mean that permission from parents should not be required when the



participants are adolescents.

But what age determines when someone can consent for himself or herself to participate in research? Shapiro and Ossorio point to the Common Rule, a set of federal regulations which provide protection for human participants in research studies, and provides the basis for allowing adolescents to provide consent without parental permission. These regulations state that existing laws determining who can consent to participate in an activity (such as STD testing or SNS participation) also determine who can consent to participate in research about that activity.

In the absence of established regulations and close scrutiny of how the patchwork of existing regulations apply to SNS research, some IRBs (internal committees established to ensure compliance with federal regulations regarding the welfare of human subjects) categorize adolescents as children, says Shapiro and Ossorio. But the researchers note that the federal Children's Online Privacy Protection Act (COPPA) permits minors aged thirteen and up to consent to participation in online media in the same manner as adults. They also point out that Facebook and other social network sites have policies that prohibit access to users under 13.

"This suggests that 13 is an acceptable threshold for consent," says Shapiro. "However, we are not suggesting that parents of adolescents are waiving their rights and should be excluded from the process."

"Parents can read information about the research and ask questions and are certainly free to prevent their child from participating," he explains. "But we believe that current regulations mean that adolescents should not be categorized as children and can provide consent themselves." He notes that consent is required for children younger than 13.

Another question addressed in their paper involves privacy. Typical



Facebook users may have connections to a large network of "friends." Is it ethical for researchers to have access to information about a participant's Facebook friends that is collected as part of an experiment? What information, particularly identifiable data on someone other than the study participant, is considered private? What processes should researchers follow to protect privacy while still conducting important research?

"Given the unprecedented ability of online research using social networks to identify sensitive personal information concerning the research subject and the subject's online acquaintances, researchers need clarification concerning applicable ethical and regulatory standards," Ossorio says.

At the moment, there are many questions and few consistent answers. The Common Rule, Facebook and regulatory authorities have different standards as to what information is private. "Social conventions regarding information privacy on SNSs are still developing, so people's expectations of privacy may be in flux," says Shapiro. He also notes that the courts have not yet considered all aspects of online privacy.

Shapiro will be the inaugural holder of this professorship which is part of a \$3 million gift from the James S. McDonnell Family Foundation to Tufts' Center for <u>Engineering Education</u> and Outreach. The foundation is named for the noted aviation pioneer and founder of McDonnell Aircraft Corporation, which later became McDonnell Douglas Corporation.

In addition to the professorship, the gift will support efforts by the CEEO to expand research into educational technologies to help children in grades K-12 learn engineering and technology concepts in the classroom.



**More information:** "Regulation of Online Social Network Studies," R.B. Shapiro and P. N. Ossorio, *Science* 339:144-145 (2013)

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