

## **UMASS GLOBAL INSTITUTIONAL REVIEW BOARD**

### **UMASS GLOBAL IRB Policy Regarding Research Using Social Networking Websites**

The term “social media” refers to modes of communication that allow researchers to utilize computer and Internet-based methods of collecting, storing, utilizing, and transmitting data in research involving human participants. As these new methods become more widespread in research, they present new ways of enhancing the management of surveys to human research participants while also presenting new compliance challenges to the protection of those participants.

The Food Drug Administration (FDA) and the Office for Human Research Protections (OHRP) have provided little guidance on the use of these new avenues of communication. However, even if new guidance is issued, it is unlikely to change the basic principles guiding institutional review boards (IRBs) in ensuring that appropriate safeguards exist to protect the rights and welfare of research participants. (Gearhart, 2012)

The principles underlying basic human subject protections require that IRB review the content of study-specific communications before they are posted. These principles also require that the IRB understand how the researcher will collect and protect confidential information.

#### **IRB Review**

Recruiting activities are the beginning of the informed consent process and, as such, are subject to IRB review to ensure that they are accurate and not misleading. The IRB also must ensure that recruitment materials are not “unduly coercive” or promise or imply a certainty of cure or other benefit beyond what is contained in the protocol and the informed consent document. The IRB must review all direct advertising for research subjects—“advertising that is intended to be seen or heard by prospective subjects to solicit their participation in a study. In the world of social media, this includes display or banner ads, which are solicitations that often appear along the top or right-hand side of a web page. Direct advertising also includes “rich media advertisements,” which involve an element of interactivity, such as a rollover, scroll bar, or click for more information.

The IRB also must review paid search advertisements, in-text advertisements, and advertisements appearing on social networks such as Facebook, MySpace, and LinkedIn. If a researcher establishes a social network page to promote a study, then that page should be reviewed. Any blog, blog post, tweet, or text that contains study-specific direct advertising should be submitted for review. Twitter can be used to solicit information; comments can be posted on a Facebook wall; and individuals can be asked to submit personal data on a website page. When a researcher collects information about an individual, federal regulations require the IRB to ensure “there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data.” As explained by OHRP, “[i]f identifiable

private information is collected via the clinical trial website, the IRB should review plans for protecting the confidentiality of that information. The IRB should ensure that the website clearly explains how identifiable private information might be used.

Current regulations and guidance set forth enduring principles regarding the protection of human research participants, such as the protection of individuals from coercive, inaccurate, or misleading communications and the protection of individuals' confidential health information. For as long as researchers hold these principles to be valuable, the IRB has a role in conducting prospective review of proposed research activities. Emerging technologies in social media provide powerful new tools for researchers, and researchers should be able to take advantage of these tools by working closely with their IRBs to develop appropriate social media communication plans.

Gearhart, C. (2012). IRB Review of the Use of Social Media in Research. *Monitor* 39-42

Cornell University. Office of Research Integrity and Assurance. (2013) COMPUTER – AND INTERNET-BASED HUMAN PARTICIPATION SURVEY RESEARCH