# Research in a Private Online Setting

While it is increasingly difficult to claim that any information that is posted online is truly “private,” there are online sites where the members have an expectation that their information will remain private. Within that context, what are the ethical considerations, and how do researchers meet the federal requirements for protecting human subjects?

The Secretary’s Advisory Committee on Human Research Protections (SACHRP) recently (March 2013) published their draft comments regarding ethical consideration associated with Internet Research. Below are some of their comments that address what is considered “private information.” (From pages 5-7 of [SACHRP document](http://www.hhs.gov/ohrp/sachrp/mtgings/2013%20March%20Mtg/internet_research.pdf)):

* “Investigators and IRBs should remember that the Belmont Report’s fundamental principles of respect for persons, beneficence, and justice are as applicable to Internet research as they are to any other form of human subjects research. Regardless of how the regulations may be interpreted in individual studies, adherence to these fundamental principles is important to encouraging public trust in the ethical conduct of Internet research.” (SACHRP, page 2-3)
* Private information as defined in the Common Rule means ―information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, and information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (for example, a medical record). [45 CFR 46.102(f)]
* If individuals intentionally post or otherwise provide information on the Internet, such information should be considered public unless existing law and the privacy policies and/or terms of service of the entity/entities receiving or hosting the information indicate that the information should be considered ―private. To the extent that terms of service or explicit prohibitions would preclude the use of data on the Internet for research purposes, the determination that such data should be considered ―private is clear.
* In addition, investigators should note expressed norms or requests in a virtual space, which – although not technically binding – still ought to be taken into consideration. When in doubt about whether to consider data public or private, investigators are encouraged to consult with their IRB about the specific circumstances. IRBs should be aware of changing terms, site security, and information/data use policy. For example, what was once considered private information may change based on the business model of the site.

**CSU IRB Requirement:** If you will be conducting research with participants in a private online site, please remember to submit the letter or email of agreement from the site administrator that indicates you have permission to conduct research with individuals who use the website.

As with social media research, it would be helpful for the IRB reviewers to see a snapshot of the website you will be recruiting from so that the reviewers can have a better understanding of that particular site’s architecture. Letting the IRB see the online environment will help facilitate the review process.

## Website suggestions from the presenters included:

[SACHRP](http://www.hhs.gov/ohrp/sachrp/mtgings/2013%20March%20Mtg/internet_research.pdf)
[Fred Cavazza](http://www.forbes.com/sites/fredcavazza/)
[Univ. of S. California IRB](http://oprs.usc.edu/education/internet/)
[Association for Internet Researchers](http://ethics.aoir.org/index.php?title=Main_Page)