

Liberty University Institutional Review Board

Guidelines for Internet Research with Human Subjects

The Internet has become increasingly prominent as a research tool although specific regulations for Internet research compliance are currently only in their early developmental stages. In the absence of rules and policies, researchers and IRBs must use their sense of ethical empathy to adequately protect the rights and welfare of human subjects to guide research design and execution. Information provided by the Internet usually includes, but is not limited to, email, websites and bulletin boards.

Generally, Internet-based research should be subject to the same ethical principles as more traditional research with human subjects. Beneficence, justice and respect for persons are paramount. Internet researchers have moral obligations to respect and protect human beings as autonomous agents and thereby to protect human dignity (Ess, 2002). Briefly, Internet researchers must:

- Do no harm,
- Protect the anonymity of subjects,
- Protect the confidentiality of all research data tied to the identity of subjects,
- Obtain informed consent from subjects.

Public or Private Space?

The Internet is generally considered a public domain, easily accessible to anyone, yet many Internet community members regard their online interactions to be private conversations embedded in public space. Researchers must be sensitive to the issue that whether a space is public or private is relative to the definitions of those who occupy it (Cavanagh, 1999) and be aware of the implications resulting for the informed consent process.

Psychological harm can result when members are unaware that they are being analyzed and when the results of the study are published in a way that allows the participants to identify themselves and their community. Community members have reported feelings of betrayal, intrusion and anxiety. This is especially true for vulnerable populations such as support groups for HIV patients, sexual abuse survivors, or alcoholics anonymous. Researchers should therefore consider the community's nature and level of accessibility (e.g., is membership required, log-on id's, extent of member profiles) to help them determine the level of privacy expected by the community members.

Informed Consent Process

If informed consent is required, researchers face the logistical challenges of the Internet. Virtual communities can include several hundreds of participants, either actively involved as long-term members or as one-time participants. Contacting each member is problematic. In this case, the community leader can serve as the initial contact to discuss the proposed research study and the informed consent process. At a very minimum, informed consent should be obtained from the core members of the community.

Email seems to be an acceptable medium for the informed consent document. However, the validation of the virtual informed consent process proves difficult because the direct researcher/subject interaction is missing; the actual age, mental competency, and comprehension of the potential subject are not known. The issue of authenticating informed consent remains

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unsolved at this time. At a minimum, though, researchers in all studies are encouraged to identify their positions from the outset of the research study.

If deception is considered necessary by the PI and the IRB, it must be followed by a debriefing of the participants; however, in Internet studies it is difficult to ensure that all individuals involved are included in the debriefing process. Currently this issue is being raised and reviewed by a variety of research ethicists. Due to the complexity of the issues regarding informed consent in Internet research, IRBs are strongly encouraged not to be hesitant to raise the level of review and the acceptable standards for regulatory requirements beyond the minimum when deemed necessary.

Privacy and Confidentiality

The seeming anonymity of the Internet appears to fulfill a researcher's obligation to protect subjects' privacy and confidentiality to prevent harm, but researchers should be aware that Internet technology allows one to store and archive online communications and makes this information available at relatively low cost and ease of use to facilitate the tracking of participants. It is possible to trace member citations to their email addresses and thus reveal their true identity. Confidentiality can also be compromised during data transmission and storage either through human or computer error.

Pseudonyms, while sufficient to disguise a person's identity in the physical world, may serve as a real identity in the online world. Members often exert special care in developing their online identity, which can be easily identified by community members when research results are published.

In a nutshell, researchers must make their research goals clear to the members of the community where they undertake their research and gain the informed consent of their consultants beforehand. It is also important to learn whether the group would prefer to be named in the written report of the research or given a pseudonym and to offer the results of the research if informants would like to read it. Most of all, researchers must be sure that the research does not harm or exploit those among whom the research is done.

Participation of Minors

The complexity of the virtual world presents researchers with the challenge to protect children during Internet research whether or not the children are the intended subjects. There are no proven methods at this time to effectively validate age through electronic communication. Informal federal guidelines suggest it is insufficient to merely ask participants to state whether they are age 18. IRBs and researchers are therefore encouraged to devise supplemental methods of identifying a subject's age via the Internet.

When children are recruited as subjects of an Internet study, researchers should obtain parental consent in addition to the child's assent, but there are no clear and distinct suggestions from authorities and the research community for more concrete guidance at this time. The current technology is not equipped to address some of the ethical issues raised by Internet research. It is therefore most important that IRBs exercise cautious deliberation on any research that involves children and do not hesitate to raise the regulatory bar when necessary.

Ethical Implications

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While the Internet as a research medium is being reviewed, and binding regulations and policies are still in their formative stages, it falls in the empathetic sensibilities of IRBs and researchers to determine what affected research participants would hope for in terms of reasonable expectations regarding human subjects protection. It certainly behooves researchers and IRBs to extend the imaginative range and to identify with those most affected by their research. Albert Schweitzer synopsized the ultimate precondition needed to overcome the empathetic divide between researchers and the subjects: "The first step in the evolution of ethics is a sense of solidarity with other human beings." Becoming the other is the crucial step at this point (i.e., what would you reasonably expect in terms of protections when specific data about yourself is being used in a particular research project).

Issues to Consider for Researchers & IRBs

Following is a list of considerations for both researchers and IRBs when designing and reviewing Internet-based studies (Eysenbach & Till, 2001):

- **Intrusiveness:** To what degree is the research intrusive? Is it a passive analysis of postings or active involvement in the community?
- **Perceived privacy:** What is the level of perceived privacy of the Internet community?
- **Vulnerability:** Who are the members of a community? For example, sexual abuse survivors and cancer patients would be classified as a highly vulnerable population.
- **Potential harm:** Would the intrusion of a researcher or publication of the results have the potential to harm individuals or the community as a whole?
- **Informed consent:** Is informed consent required or can it be waived? If required, how will it be obtained?
- **Confidentiality:** Are verbatim quotes given that would identify the originator? How can the anonymity of participants be protected?
- **Intellectual property rights:** Where participants seek publicity, not anonymity (e.g., scholarly/academic discussions on the Internet), the use of postings without attribution may not be appropriate.

References

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