

Guidance and Procedures Number: 44
Title: Research Involving the Internet
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I. Introduction

Research involving human subjects falls under the purview of the OPRS/IRBs, even if data collection takes place over the Internet using methods such as email, listservs, electronic bulletin boards and web surveys. IRB approval or Certification of Exemption from IRB review is necessary whenever conducting research involving human subjects.¹

The UCLA IRB/OPRS will review the use of the Internet for research activities, including subject recruitment, under its jurisdiction to ensure that:

- (1) Risks such as violation of privacy, legal risks, and psychosocial stress are minimized;
- (2) Subjects' participation is voluntary;
- (3) Informed consent requirements are met; and
- (4) Information obtained from or about human subjects is kept confidential.

II. Informed Consent Process for Internet-Based Research

- A. For anonymous Internet-based surveys, it is sometimes appropriate to provide subjects with informed consent information, and inform subjects that submitting the completed survey implies their consent. Alternately, Internet-based surveys could include "I agree" or "I do not agree" buttons with which participants would indicate their active choice of whether or not they consent to participate.
- B. If the UCLA IRB determines that documented consent is required, the researcher may email the consent form to participants who may then type their name and the date into the spaces provided on the consent form, and return it to the researcher via email.
 1. In order to allow typing of names and dates into the consent form, researchers are allowed to provide participants with a version of the consent form that does not include the IRB approval stamp. This exception is allowed so long as the content of the consent form is exactly as approved by the IRB.
- C. Researchers conducting web-based research should be careful not to make guarantees of confidentiality or anonymity, as the security of online transmissions may not be guaranteed.

¹ See [HRPP Guidance & Procedure # 2: Determining When Research Activities Require UCLA IRB/OPRS Review](#) for details regarding when an activity is research involving human subjects.

- D. Researchers should inform subjects that "observation" is taking place, and that any information exchanged may be used for research purposes when observing a chat room that is not open to the public.
- E. Online consent may not be suitable for high risk studies where the research involves data that:
 - 1. places subjects at risk of criminal or civil liability, or
 - 2. could damage their financial standing, employability, insurability, reputation, or
 - 3. could be stigmatizing.

III. Requirements for Consideration of Data Collection and Security

- A. All data must be protected as it moves along the communication pathways (e.g., from the participant to the server, from the server to the Investigator). Additionally, all databases storing identifiable information or data must be protected regardless of the source creating the data (e.g., encryption of the database, de-identifying the data).
- B. The IRB must review and approve the method and procedures for data collection and security.
- C. Investigators must provide information regarding the transmission and storage of the data.
- D. When an Investigator chooses to have a separate server for data collection or storage, the IRB must review and approve its administration.
- E. The level of security should be appropriate to the risk. Research involving sensitive topics may require additional protections such as certified digital signatures for informed consent, encryption of data transmission, or technical separation of identifiers and data.

IV. Use of the Internet for Subject Recruitment

- A. The IRB must review and approve all materials used for posting recruitment materials on the internet, e.g. through a website, a banner advertisement, or an email solicitation.
- B. Computer- and internet-based procedures for advertising and recruiting potential study participants (e.g., internet advertising, e-mail solicitation, banner ads) must follow the IRB guidelines for recruitment that apply to any traditional media, such as newspapers and bulletin boards (see [HRPP Guidance & Procedure # 30: Recruitment Methods & Tools](#) for details).
- C. Investigators requesting to recruit through UCLA's mass email system must follow the appropriate UCLA policies and procedures for review and approval in addition to obtaining IRB/OPRS approval for the recruitment procedure and message content. (See [HRPP Guidance & Procedure # 30: Recruitment Methods & Tools](#) for details).

V. UCLA IRB/OPRS Requirements

- A. The IRB must review all research activities involving the use of the internet with the same considerations and standards for approval of research (45 CFR 46.111), for informed consent, and voluntary participation as all other research activities under the jurisdiction of the UCLA IRB.
 - 1. The IRB must evaluate the appropriateness of the informed consent process according to Section II above.
 - 2. The IRB must take into consideration data collection and security as described in Section III above.
- B. The IRB review must include a consideration for the delineation of boundaries (i.e., would the participant consider the access private or public space of the internet).
- C. The IRB must consider all additional requirements for the approval of research that involves a vulnerable population as all other studies recruiting those populations.
- D. As there is no standard for identifying distressed participants online, the IRB must take into consideration potential participant experiences (the sensitive nature of the research) that may be distressing when evaluating the risk/benefit ratio.

VI. Investigator Requirements

- A. Researchers should design research protocols which use the internet with the same considerations and standards for approval of research (45 CFR 46.111), for informed consent, and voluntary participation as all other research activities under the jurisdiction of the UCLA IRB/OPRS.
- B. Researchers should format online survey instruments in a way that will allow subjects to skip questions if they wish to or provide a response like "I choose not to answer".
 - 1. Similarly, at the end of an online survey, subjects should be able to either discard the data or to choose to submit it for inclusion in the study.
 - 2. If applicable, online surveys must include mechanisms for withdrawal. For example, if a participant decides to withdraw, there should be a mechanism for identifying the responses of a participant for the purposes of discarding those responses.
- C. Researchers working with children online are also subject to the Children's Online Privacy Protection Act (COPPA) (<http://www.ftc.gov/ogc/coppa1.htm>) . *COPPA prohibits researchers from collecting personal information from a child without posting notices about how the information will be used and without getting verifiable parental consent.*
 - 1. Researchers conducting research which excludes minor subjects should describe the procedures to be employed to authenticate that the participants are adults.
- D. Researchers should provide appropriate payment which allows subjects to receive an incentive without revealing his/her identity. (e.g., gift certificates from online retailers)

provided by displaying the unique certificate redemption number to respondents at the completion of a questionnaire.)

- E. Researchers should describe methods to authenticate respondents when necessary, e.g., to protect subjects' privacy. (e.g., Researchers can provide each subject (in person or by U.S. mail) with a Personal Identification Number (PIN) to be used for authentication in subsequent computer- and internet- based data collection.

Regulations:

45 CFR 46

References:

Ethical and Legal Aspects of Human Subjects Research in Cyberspace: a report from the AAS Program on Scientific Freedom, Responsibility and Law, in collaboration with NIH/OPRR. (<http://www.aaas.org/spp/sfrr/projects/intres/report.pdf>)

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