

# Internet Research

Internet based research is no different than other human subjects research in terms of regulatory oversight and requirements. Human subjects research that is designed to recruit participants or collect data through the internet must be reviewed by the IRB. Below are recommendations and cautions about conducting research online.

## Consent and Privacy Online

Not all content on the internet is “public information”. Depending on the sensitivity and identifiability of the research data, the IRB may require informed consent be obtained from subjects. Consent must always be obtained for collection of private information\*. Researchers should tell participants if they are required to report any photos revealing child or elder abuse or the likely prospect of harm that a subject may inflict on themselves or others. A waiver of informed consent can be requested from the IRB, as appropriate.

*\*private information* is behavior that occurs in a context in which individuals can reasonably expect that no observation or recording is taking place

## Tips for online consent

- Establish procedures to ensure that research participants are adults.
- Instead of a signature line, the consent can state, “By completing the survey, you are agreeing to participate in the research.” Web based surveys should offer subjects the option to “Agree”/“Not Agree.”
- For sensitive data, the investigator should include a disclosure in the consent process, such as: “This research involves the transmission of data over the internet. During online communication security of information cannot be guaranteed.”
- An alternative means for completing the survey should be offered where appropriate, such as printing the survey and mailing it.
- Allow participants to skip questions or provide a response such as “I choose not to answer.”
- To ensure that a subject may withdraw at any time provide at the end of the survey, a button to submit the data and another button to discard the data.

## Working with Children Online

- Investigators communicating with children over the internet are subject to the [Children's Online Privacy Protection Act \(COPPA\)](#) in addition to human subject regulations ([45 Part 46 Subpart D](#)). Investigators must not collect personal information from a minor without verifiable parental consent.
- As appropriate, technology may be used to help screen out minors, such as Adult Check systems.
- The data file used for data analysis should be free of IP addresses or other electronic identifiers. If IP addresses are collected by the survey tool, the addresses should be deleted from the downloaded data file.

## **Challenges of Online Research**

### **Research Recruitment Online**

The text and context of the recruitment message must be reviewed and approved by the IRB before the research begins. Research activities include posting recruitment information to a message board, sending an e-mail blast, or launching a webpage for recruitment.

### **Control over Data-Collection Setting**

- When surveys or experiments are online, researchers have limited control of the environment in which the research is conducted.
- Behavioral monitoring and verification of subjects' identities, age or gender present increased challenges.
- Subjects may invest less focus in an online research task than those involved in a telephone survey or laboratory experiment.

### **Online culture of sharing**

- The participants should know what information the researcher has/will collect. Boundaries should be clear regarding what information will be gathered.
- Public posting of patient protected health information is a violation of the Health Insurance Portability and Accountability Act (HIPAA) therefore, health information should be especially safeguarded online.
- Posting pictures of patients (including those taken in international sites) is a potential violation of patient privacy.
- If participants were to look at the researcher's Facebook profile or conduct a "Google" search on her prior to the first study visit might this impact how they answer questions.

- Using images created of or by research participants can become complex as issues of consent, anonymity, and copyright come into play.

## **Compensation Online**

### **Compensating Anonymous Subjects**

- Do not link compensation to contact information.
- Use an intermediary service to manage your compensation.
- In lieu of requiring identifiable information, provide gift certificates from online retailers that display a unique certificate redemption number after the survey is completed

### **Tips for Online Reimbursement**

1. Offer compensation comparable to that of similar research.
2. Plan your budget to account for online platform fees.
3. Develop an information sheet that participants can review. Include a list and description of tasks, as well as a clear explanation of the compensation provided.
4. Consider letting online respondents review the survey or the task before they decide to participate.
5. Schedule reimbursements to be received as soon as possible after participation, and so inform subjects.
6. Offer follow-up survey tasks as “optional”, with separate compensation schedule.
7. If compensation is low, consider offering a prize drawing on top of it.
8. Maintain clear financial records of reimbursements.
9. Generously estimate time to complete tasks so participants do not exceed estimated time and compensation is appropriate.
10. Subject retention is statistically only 50%, for follow up tasks so plan accordingly.