

PARTNERS HUMAN RESEARCH COMMITTEE

Guidance on Research Using the Internet Survey Research Using Web-Based Survey Tools

Increasingly, investigators are using web-based survey tools to collect data from research subjects. Recent examples of research using the internet include:

- Web-based survey of the effects of Inflammatory Bowel Syndrome on Quality of Life
- Collection of clinical data from parents of children with Autism Spectrum Disorders
- Survey of ophthalmologists regarding usefulness of new technique
- Employee surveys/QI research

Internet-based research must meet the same criteria for IRB approval and offer the same level of protections to human research subjects as research conducted through more traditional methods. When the IRB reviews the use of web-based survey tools, the IRB must specifically consider whether the web-based survey tool affords adequate privacy and confidentiality protections and ensures that additional risks related to Internet research are minimized.

Determination of Risks Involved in Web-Based Surveys

Whether an individual is identifiable or anonymous has important implications for the determination of risks involved in the research. Many third-party survey sites collect IP addresses, email addresses or other identifiable data, which would allow these survey sites to trace survey response data back to individual responders. The ability to trace responses back to individuals via their e-mail address, their IP address, or other information captured while visiting the survey website is of concern to the IRB and to participants. Therefore, when choosing web-based survey tools, you should choose a tool that allows you to assure respondents that you will not capture information that they do not voluntarily provide.

In addition, the sensitivity of the data being collected must be considered when determining the risks to subjects' privacy and confidentiality. If an invasion of privacy or a breach of confidentiality would reasonably place subjects at risk of embarrassment or harm, including criminal or civil liability, or be damaging to their financial standing, employability, insurability, reputation, or be stigmatizing, it may be unacceptable to collect sensitive data online via the internet without encryption or other methods that guarantee anonymity. If, however, the information would bring no harm or embarrassment to subjects if revealed, there may be less concern about anonymity, and the use of externally-hosted online survey methods (Survey Monkey, etc) may be acceptable. Please be aware that with certain stipulations (i.e., the survey will not collect identifiable information, such as name, address, email, or IP address as part of the survey or when visiting the site) you may be able to guarantee anonymity when collecting data online via the internet; however, in most cases, you will only be able to assure confidentiality.

Online Survey Tool Recommendations for Research Projects

For information on acceptable survey and data capture tools and data security, please refer to the [Partners Information Systems guidelines](#).

General Guidelines for Preparation of IRB Submissions Involving Web-Based Survey Tools and Internet Research

Please consider the following in planning online data capture and internet research:

- Consider keeping identifying information (names, addresses, emails) in one file, and data in a second. Use an arbitrary code number to link the two.
- Consider validity of data and the possibility of people completing surveys multiple times. Will you utilize methods to authenticate, track or restrict access to the Web survey (e.g., further verification of appropriateness of subject answering questions)?
- Consider offering alternative methods of participating in the study if subjects prefer not to submit their information online.
- When applicable, follow legal requirements for obtaining permission to use copyrighted instruments in your online research.

Protocol Summary

In your Protocol Summary, be sure to address each of the following questions, when relevant, in the applicable section.

Research Design and Methods:

- Name the survey tool you plan to use (e.g., RedCap, LimeSurvey, Survey Monkey).
- Discuss plans for pilot testing or pretesting the survey prior to posting it “live” (e.g., pretesting or paper validation).
- Indicate whether the survey is by invitation only, with a special code (login/password), or available to the public.
- Due to variation in access to computers and the Internet, some otherwise eligible individuals will be excluded from Internet-based research. Address any bias introduced by conducting research over the Internet.

Privacy and Confidentiality

- Indicate whether directly identifiable information (names, addresses, emails) will be kept in one file, and data in another or whether an arbitrary code number will be used to link identifiable information and the data.
- When using survey tools such as Survey Monkey to collect information that is not PHI or personal or sensitive information, indicate that you will purchase SSL encryption, change survey settings so that respondent’s IP addresses are not saved, obtain a copy of the database, delete copies of the database from vendor servers and backups, and document study staff access to survey account details in the research record (see [Partners Information Systems guidelines](#) for more information).