

PARTNERS HUMAN RESEARCH COMMITTEE

Guidance on Research Using the Internet Informed Consent in Online Research

IRBs may waive the requirement for written documentation of informed consent when the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context or when the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Online research involving adults often meets one of these conditions. A consent procedure in which subjects are provided with a written statement about the research followed by a button to click that states, "I AGREE TO PARTICIPATE IN THIS RESEARCH" is often acceptable.

Include the following information in the written statement about the research, when applicable:

- This is a research study
- Title of the study
- PI name
- Purpose of the research
- Sponsor of the research
- How you obtained their name and contact information
- Why you are asking them to participate, and how many people will participate
- How long it will take to complete the survey
- Remuneration, and how it will work (e.g., collection of SSN for this purpose)
- Discussion of extent of confidentiality and data security and risk of a breach of confidentiality
- Discussion of sensitive information being collected, and how this will be handled, when applicable
- Information about them that will be gathered from other sources (e.g., medical records)
- Participation is voluntary and can stop at any time
- Deciding not to participate won't affect medical care they receive at Partners now or in the future, or any benefits they receive now or have a right to receive
- PI contact information for questions
- IRB contact information: "If you'd like to speak to someone not involved in this research about your rights as a research subject, or any concerns or complaints you may have about the research, contact the Partners Human Research Committee at 617-424-4100."
- Add this statement when collecting Protected Health Information (PHI) via secure sites:

We are required by the Health Insurance Portability and Accountability Act (HIPAA) to protect the privacy of health information obtained for research. This is an abbreviated notice, and does not describe all details of this requirement (see Partners Privacy Notice). During this study, identifiable information about you or your health will be collected and shared with the researchers conducting the research. In general, under federal law, identifiable health information is private. However, there are exceptions to this rule. In some cases, others may see your identifiable health information for purposes of research oversight, quality control, public health and safety, or law enforcement. We share your health information only when we must, and we ask anyone who receives it from us to protect your privacy.*

**Partners HealthCare Notice for Use and Sharing of Protected Health Information*

http://www.partners.org/Assets/Documents/Notices/Privacy_Notice_English_8-11-08.pdf

For more information on internet research and informed consent, refer to the [Partners Information Systems guidelines](#).