

Collecting Human Subject Research Data via the Internet Including Sample Informed Consent

Studies that collect data via use of the internet (e.g., email, web based surveys) require special consideration from the IRB which should have at least one member with professional expertise in conducting human subjects research. The use of the internet and email for data collection will pose challenges in collecting a) anonymous data, b) obtaining informed consent and c) ensuring that participants are of the appropriate age to give informed consent. The research plan and Form 4 must explicitly address how these challenges were evaluated and addressed.

It is permissible to develop a process of obtaining informed consent that is conducive to internet research. Researchers will want to provide information to potential participants about the purpose of the study and nature of their participation, potential risks, the voluntary nature of the study and the participant's right to withdrawal from the study at any time. A sample informed consent statement for adult participants is shown below. The text in italics provides an example of appropriate wording. If privacy and/or confidentiality are of particular concern, an alternative to asking participants to provide their name is also demonstrated.

Recruiting and utilizing participants who are under the age of 18 for a research study conducted on the internet is permissible under the two following conditions.

- a. If the IRB has determined that informed consent is required, the parent/legal guardian must give consent through a traditional Form 4 and informed consent procedures. In this situation, parents/guardians review and sign a Form 4 before the minor participant completes the online or email survey.
- b. If the IRB determines that informed (parental) consent is not necessary for a study that poses very minimal risk, the student researcher can use an assent procedure similar to the consent form detailed below. The researcher should provide information to potential participants describing the nature of the study and what the participant will be asked to do, informing the participant of his/her right to withdrawal at any time and indicating that by typing I AGREE or checking a box on the survey and completing the survey, he/she has agreed to participate in the study.

Sample Internet Informed Consent Text for Adult Participants:

In order to decide whether or not you should agree to be part of this study, you should understand enough of its risks and benefits to make an informed judgment. This process is known as informed consent. This consent form gives you detailed information about the research study. Once you understand the study, if you still wish to participate, you will be asked to electronically sign this informed consent form.

Title of Study:

Name & Contact Information of Student Researcher & Qualified Scientist (if applicable):

Purpose of the Study:

Duration: *My participation in this study will include the completion of this online survey.*

Procedures: *During the course of this study, I will be asked to complete this online survey.*

Potential Risks/Discomforts:

Potential Benefits:

Confidentiality: *All responses to this survey will be kept confidential. Your name or identity will not be linked in any way to the research data.*

Right to refuse to withdraw: *I understand that my participation is voluntary and I may refuse to participate, or may discontinue it at any time.*

Individuals to contact: *If I have a question about my participation in this study, I can contact:*

I have read this entire form and I understand it completely. All of my questions regarding this form or this study have been answered to complete satisfaction. I agree to participate in this research.

I understand that by typing my name in the box below I am signing this form and therefore am providing informed consent for this study.

Alternatively, if confidentiality of responses is a concern the following text could be used:
By typing the words I AGREE in the space below and by completing the attached survey I am giving my consent to participate in this study.