

## Surveys and Human Subjects' Research/IRB – About Anonymity and Confidentiality

The IRB receives many questions about whether a survey conducted as part of human subjects' research (HSR) is considered anonymous. Those considering surveys as part of HSR projects should review the guidance below.

### ***First, About Anonymity***

It is important to understand that the IRB considers anonymity, and whether investigators have or are obtaining personally identifiable information, for several purposes, including: determining which level of IRB review will be required; reviewing whether investigators are applying appropriate data protections as part of the research process; and evaluating the appropriateness of language used in subject recruitment, informed consent, and other communications and materials.

### ***Is My Study Anonymous?***

Under the University's IRB policy, for a **study** to be anonymous, no one, including the researcher, **has or collects any personally identifiable information or data** (e.g., name, address, telephone number, etc.) that identifies individual participation *or* links responses to a specific individual, at any time.

- In considering IRB applications for the purposes of review classification (Exempt, Expedited, Full) the University's IRB considers that **anonymity applies to the research study as a whole**. This includes all components – research design, methodology, recruitment processes, communications with subjects, informed consent procedures and documentation, and other elements.
- **If any one aspect of the study includes personally identifiable data, the study cannot qualify as exempt research**. This may include using individual emails to recruit participants; individually identifiable responses gathered via interviews or surveys; or gathering names/signature on submission of consent forms.
- Many research projects include surveys (usually done electronically). Even if a *survey* is considered anonymous (see below), if personally identifiable data is part to any aspect of the study of which it is part, the *study* will not be considered anonymous and cannot qualify as exempt research.
- Sometimes researchers may wish to change their research approach during a study. Even if a study is determined to be exempt, any change to the research requires additional review by the IRB before it can proceed. Such changes may have the potential to change the review level/classification.

The following guidance may assist researchers in determining how survey design fits into the IRB review process.

### **Surveys: Anonymous or Not Anonymous?**

#### ***Anonymous Surveys:***

- A survey link is provided via an entirely anonymous format (e.g., poster with QR code, generic social media post); has any IP settings disabled; does not gather any personally identifiable information, or a combination of identifiers that may make it more likely to identify an individual, from participants for any purpose.

*This information is limited solely to providing supplemental information for researchers considering an application for IRB review. It does not replace or in any way supersede content addressed in federal regulations and/or the official University of Scranton IRB Policy and associated procedures, nor does it serve as official guidance or judgment for specific research projects and IRB applications. The official IRB policy and other official resources are available via the [IRB Website](#).*

- A link to a survey is sent to a listserv, or posted via a professional site/interest board; has any IP settings disabled; responses are submitted directly to a survey software package (not returned via email); does not gather any personally identifiable information for any purpose, or a combination of identifiers that may make it more likely to identify an individual; and individual respondents' responses/data cannot be linked to their email or any other personally identifiable information or combination of identifiers.

As these methods of delivery do not include individually identifiable data, unless other aspects of the study meet the requirements of Expedited or Full review, the study may qualify as exempt. Investigators may refer to the survey as anonymous in research communications.

### ***Recorded Anonymously***

- A link to a survey is sent to an individual email address(es); has any IP settings disabled; responses are submitted directly to a survey software package (not returned via email); does not gather any personally identifiable information for any purpose, or a combination of identifiers that may make it more likely to identify an individual; and individual respondents' responses/data cannot be linked to their email or any other personally identifiable information or combination of identifiers.

As this method of distribution means that investigators have individually identifiable data (email addresses), the study will not qualify as Exempt and will be reviewed using the Expedited review process, unless other aspects of the study qualify it for full review. Investigators may say "Your responses to this survey will be recorded anonymously and will be handled in a confidential manner."

### ***Not Anonymous***

- The survey includes a signed informed consent form.
- The survey, distributed in any manner, gathers personally identifiable information, including optional email addresses for the purpose of follow up communication (reminders, distribution of incentives, etc.), or a combination of indirect identifiers (such as demographics) that may make it more likely to identify an individual.
- The survey, if distributed electronically, includes any IP setting that may potentially identify a specific respondent(s).
- The survey, if distributed via email, is done in such a manner that the recruitment pool may see email addresses for other potential participants.
- The survey link is distributed via email and responses are sent back via email, even if it does not gather any personally identifiable information.
- If processing of data, such as summary or analysis methods that identifies respondents by a group where the N of the group is so small that individual respondents may be more likely to be identified.

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The above examples would not be anonymous, as the investigator can identify individual participants/respondents, even if the investigator has collected no other identifying information. Investigators may say that “Your responses to this survey will be handled in a confidential manner.”

*Additional Guidance:*

- In all cases, remember that research subjects must have the option to skip questions. Investigators should be sure to design/program the survey so that there are no questions where an answer is required.
- In cases where the survey is distributed electronically, one risk of participation is that a breach of confidentiality always exists for any information sent via electronic media. Investigators should include this information in informed consent materials.