PRIVACY AND CONFIDENTIALITY

Description

When thinking about privacy and confidentiality in the research context, distinctions should be made between the two issues.

Privacy refers to persons and to their interest in controlling access of others to themselves. Privacy can be thought in terms of having control over the extent, timing, and circumstances of sharing oneself (physically, behaviorally, or intellectually) with others.

Confidentiality is an extension of the concept of privacy, but it refers to the research participant’s understanding of (and agreement to) the ways that their identifiable information will be stored and shared. Identifiable information can include printed information, electronic data or media, or visual information (photographs, video records, etc.).

The bottom line: Privacy refers to people; Confidentiality refers to data about people.

The following are examples of methods used to protect privacy and confidentiality. Researchers will be asked to inform the IRB about the precautions and procedures employed to protect privacy and confidentiality with regard to his/her specific project. Different levels of protection are appropriate for different studies; the researcher should assume the IRB will require the highest level of protection for the most vulnerable population included in the study.

Examples of Privacy Protections:

• Interviewing participants about sensitive topics individually instead of in front of a group.
• Interviewing the participant in their home or a private office instead of a public place.
• Providing a private exam room for study procedures.
• De-identifying photos, audio tapes, or videos tapes of the participant that will be made during the study.
• Allowing for anonymous submission of surveys and questionnaires.

Examples of Confidentiality Protections:

• Storing research data on password protected computers or in locked cabinets or offices.
• Limiting access to study data to only a few members of the study team.
• Using only encrypted systems for storing research data on laptops.
• De-identifying study data.
• Using a code number instead of the participant’s real name on study data and blood/tissue samples.
• Destroying photos, audio tapes, or video tapes at the end of the study.

Breaches of Confidentiality

Investigators are responsible for the confidentiality of participant information collected during the course of a study, including how this information will be stored and shared. A breach of confidentiality is an unanticipated problem that must be reported to the IRB. Additional requirements apply if the breach involves Protected Health Information (PHI).

Please contact the IRB Office at (801) 581-3655 or irb@hsc.utah.edu for additional guidance.
full text here
References & Links

IRB Consent Document Template

http://irb.utah.edu/forms/

Investigator Guidance Series

http://irb.utah.edu/guidelines/investigator.php

University of Utah IRB Guidance on Tissue Collection, Use and Repositories

http://irb.utah.edu/guidelines/index-tissue-banking.php

University of Utah IRB Policy on Breaches of Confidentiality

http://irb.utah.edu/submit-application/forms/breaches.php

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