

Do you know the difference between “Privacy” and “Confidentiality”?

The federal regulations differentiate between privacy and confidentiality, and it is important to understand the difference in order to determine whether these regulatory criteria for approval of human subject research are appropriately met.

Privacy relates to a Person.

Persons may not want to be seen entering a place that might stigmatize them, such as a pregnancy counseling center that is clearly identified as such by signs on the front of the building. Privacy concerns people, whereas confidentiality concerns data. The research proposal should outline strategies to protect privacy including how the investigator will access information from or about participants.

Examples of Privacy: Curtains are closed during physical examination. Health history or exam results are discussed in a private area. This may include asking an accompanying family member or friend to leave the room temporarily.

Confidentiality relates to information/data about an individual.

Confidentiality refers to the researcher’s agreement with the participant about how the participant’s identifiable private information will be handled, managed, and disseminated. The research proposal should outline strategies to maintain confidentiality of identifiable data, including controls on storage, handling, and sharing of data. When appropriate, certificates of confidentiality could be used to maintain the confidentiality of identifiable data, to allow the investigator and others who have access to research records to refuse to disclose identifying information on research participants in any civil, criminal, administrative, legislative, or other proceeding, whether at the federal, state, or local level.

Examples of Confidentiality: Lap top computers are pass word protected. Emails are encrypted. Participant files are kept locked not left unattended visibly on top of counters or desks. Patient/participant information is not shared with other research team members in an elevator full of people.

The Health Science Center IRB glossary defines these terms as:

PRIVACY: Control over the extent, timing and circumstances of sharing oneself (physically, behaviorally, or intellectually) with others.

CONFIDENTIALITY: Pertains to the treatment of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure, without permission.