

Confidentiality versus Privacy and How They Relate To Human Subjects Protections

One of the regulatory criteria for approval is: **When appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data.**

Therefore, the IRB must consider these issues as they arise during the review of a study.

Privacy is the ability of an individual or group to seclude themselves or information about themselves and thereby reveal themselves selectively. The boundaries and content of what is considered private differ among cultures and individuals, but share basic common themes. Privacy is sometimes related to anonymity, the wish to remain unnoticed or unidentified in the public realm. When something is private to a person, it usually means there is something within them that is considered inherently special or personally sensitive. The degree to which private information is exposed therefore depends on how the public will receive this information, which differs between places and over time. Privacy can be seen as an aspect of security — one in which trade-offs between the interests of one group and another can become particularly clear. Privacy may be sacrificed or knowingly “waived” to some degree when an individual decides to participate in research.

Privacy refers to persons and their interest in controlling the access of others to themselves. (Confidentiality refers to the agreement between the investigator and participant in how data will be managed and used.) For example, based on their privacy interests people want to control:

- The time and place where they give information.
- The nature of the information they give.
- The nature of the experiences that are given to them.
- Who receives and can use the information.

For example, persons might 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.

What is private depends on the individual and can vary according to gender, ethnicity, age, socio-economic class, education, ability level, social or verbal skill, health status, legal status, nationality, intelligence, personality, and the individual's relationship to the investigator. For example, protecting the privacy interests of a young child might mean having a parent present at a session with an investigator. Protecting the privacy interests of a teenager might mean having a parent absent.

Confidentiality has been defined as “ensuring that information is accessible only to those authorized to have access”.

Confidentiality in human subjects research refers to the researcher's agreement with the participant about how the participant's identifiable private information will be handled, managed and disseminated. IRB members should consider various strategies to maintain confidentiality of identifiable data, including controls on storage, handling and sharing of data. When appropriate, IRBs should also know how certificates of confidentiality could be used to maintain the confidentiality of identifiable data.

Reference:

AAHRPP tip sheet/evaluation tool and Wikipedia; federal regulations governing human subjects in research