Privacy vs. Confidentiality: What’s the Difference?

PRIVACY refers to a individual’s right to control access to him/herself. This includes access to the individual’s personal information as well as access to their body or their biological specimens.

The federal regulations define ‘private information’ as “information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, and information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (e.g., a medical record).”

CONFIDENTIALITY refers to how private information provided by individuals will be protected by the researcher from release. Describing just how the confidentiality of research information will be maintained is an important element of the consent process.

While the term ‘Confidentiality’ is not formally defined in the federal regulations, the regulations make it clear that investigators have an obligation to inform research subjects:

- how their data will be used,
- who will have access to it,
- what procedures will be put in place to ensure that only authorized individuals will have access to the information, and
- the limitations (if any) to these confidentiality procedures

These “confidentiality” requirements are part of the informed consent process, usually as part of the consent document, and thereby become part of the agreement between the researcher and the research subject.