

IRB FAST FACTS: PRIVACY & CONFIDENTIALITY

- PRIVACY is about people and where and how they share information with you
- CONFIDENTIALITY is about data and the practices for managing and protecting information

PRIVACY

Involves an individual's ability to decide what information people share and how much, where, when, and the conditions around sharing

Privacy is a concern for researchers before and during data collection:

- The way potential participants are identified and contacted
- The setting in which the participants interact with the research team
- Who is present during research procedures
- Only accessing the minimum amount of information necessary to conduct the research

CONFIDENTIALITY

Refers to the treatment of identifiable information that an individual has disclosed in a relationship of trust, with the expectation that it will not be divulged to others without permission

Confidentiality is a concern during and after data collection:

- Only authorized individuals will have access to the information
- Protect information that is collected in a manner consistent with the risk it poses to participants
- Use appropriate and secure data storage and security practices, to include full deidentification of data at the earliest feasible opportunity, encryption of data, etc.