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Privacy & Confidentiality

Privacy

Having control over the extent, timing and circumstances of sharing oneself (physically, behaviourally, or intellectually) with others

Confidentiality

The treatment of information that an individual has disclosed in a relationship of trust & 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

Justification for Privacy & Confidentiality in Research

- Respect for persons
- Beneficence

Respect for Persons

Research subjects are to exercise their autonomy to the fullest extent possible, including autonomy to privacy & to have private information identifying them confidential

Beneficence

- Risks to research subjects are minimized
- Benefits to subjects are maximized
- Risks do not outweigh benefits to subjects & others

Beneficence

- Maintenance of privacy & confidentiality helps to protect subjects from potential harms that can follow an invasion of privacy or a breach of confidentiality
- Such harms include: psychological distress, loss of employment, damage to social standing, etc.

Criteria for Approval of Research

- REC should consider the degree of privacy of the information being collected
- Explain how privacy & confidentiality of research data will be maintained

Protection of Privacy

- Face-to-face interviews:
 - provision of information in writing or by using a computer keyboard instead of orally
- Telephone: use of touch tones

Protection of Confidentiality

- Storage in locked file cabinets, offices or pass word protected computers
- Data coding with an identifier which is kept elsewhere
- Destruction of research records when the research is over

Resources & Further Reading

- Institutional Review Board: Management & Function by Elizabeth A. Bankert & Robert J. Amdur Chapter 5