

Module 5: Privacy and Confidentiality

After completing this module, you should be able to define privacy and confidentiality, have the strategies to protect participants privacy and confidentiality, and know how to identify and report breaches in privacy and confidentiality.

Privacy and Confidentiality Overview

Privacy is as an individual's right to control information about themselves. Confidentiality is considered an extension of privacy. It refers to how you keep the actual information that is gathered: who can see it, who handles it, and how it is stored.

What are potential privacy and confidentiality concerns related to your study?

What ideas do you have to address them?

Protection Strategies - Privacy and Confidentiality

Strategies for maintaining privacy and confidentiality are best laid out in the initial design stages of the study, as it will take careful planning to anticipate privacy needs.

How can you be sure to protect participant privacy needs in the following situations or environments? Choose one or more that might apply to your own study.

- Recruitment
- Site selection
- Focus groups
- Group interventions
- Sites outside clinic or institution
- Home visits
- Forms of communication
- HIPAA concerns

Data security is imperative to maintaining confidentiality. Never store information on a flash drive or other type of portable storage device and be sure to keep all file cabinets locked and computers password-protected.

Below are the privacy and confidentiality protection strategies discussed within this module. Which one could you improve in your own study?

- Data collection
- Data security
- Data sharing
- Password protection
- Limiting access to others
- Electronic backup of data
- Video and audio recording restrictions
- Transcriptions
- Certificates of Confidentiality (issued by NIH)

Does your institution have any policies regarding data security when data is being transferred using a portable storage device?

Documenting and Reporting

You must begin with a detailed plan that has been communicated with each study team member. Every person on the staff must know how to identify a breach in privacy and confidentiality and what to do when it happens.

Visit your IRB's website and note any documentation and reporting guidelines in the event of a breach in privacy or confidentiality.

What questions do you still need to discuss with your study team, IRB or IT team regarding privacy and confidentiality?

Other Notes

Resources

Certificates of Confidentiality Kiosk
<https://humansubjects.nih.gov/coc/index>

NIH Data Sharing Policy and Implementation Guidance
http://grants.nih.gov/grants/policy/data_sharing/data_sharing_guidance.htm

HHS.gov Certificates of Confidentiality
<http://www.hhs.gov/ohrp/policy/certconf.html>

HHS.gov Health Information Privacy
<http://www.hhs.gov/hipaa>

HHS.gov Office for Research Protections
<http://www.hhs.gov/ohrp/>

Protecting Respondent Confidentiality in Qualitative Research (Karen Kaiser)
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2805454>