Guidance on Privacy and Confidentiality

This guidance will assist researchers in understanding how "privacy" differs from "confidentiality", the relationship of such concepts to each other, and strategies to safeguard each of those two concepts in the context of human participant research.

'**Privacy'** refers to an *individual's* right to control access to their personal information, but it also includes access to their body (such as collection of their biological specimens). Privacy is a participant's ability to control how other people see, touch, or obtain information about the participant.

Strategies to protect one's privacy may include the following:

- The research intervention will be conducted in a private room
- Drapes or other barriers will be used for participants who are required to disrobe
- The collection of sensitive information will be limited to the minimum necessary to achieve the aims of the research
- Ensure that only authorized research study personnel will be present during research related activities.
- Ensure that only authorized research study personnel will have access to research data.
- Limit the collection of information about participants to the amount necessary to achieve aims of the research.
- Approach participants in a setting or location that preserves their physical privacy and minimizes the risk of information being overheard by unauthorized individuals.

'Confidentiality' refers to how private *information* provided by individuals in a relationship of trust, will be *protected by the researcher* from being divulged to others without permission or outside the scope of general authority. Confidentiality is therefore an extension of the concept of privacy.

Strategies to protect one's confidentiality may include the following:

- Paper-based records will be kept in a secure location and only be accessible to personnel involved in the study
- Computer-based files will be encrypted and only made available to personnel involved in the study through the use of secure access privileges and passwords
- Whenever feasible, identifiers will be removed from study-related information at the earliest opportunity, or collect data anonymously (i.e., do not gather/collect any identifiers at all)
- Audio and/or video recordings of participants will be transcribed and then destroyed to eliminate audible or visual identification of participants

Ethical Considerations

The following issues will be considered during IRB review:

- The proposed recruitment methods: How are potential participants identified and contacted? Does the recruitment plan involve access to private information, such as a medical records or student records and will permission be sought before accessing such information? Where are potential participants being approached (e.g., will others know if the prospective participant agreed to participate in the study)?
- Sensitivity of the information being collected – the greater the sensitivity, the greater the need for privacy and confidentiality.
    - Documentation of consent (i.e., participants' signature) may be waived in order to protect participant privacy. For more information on waiving documentation of consent, refer to the IRB's Informed Consent guidelines
- Method of data collection that creates unique vulnerabilities and how they are minimized in the protocol:
    - focus group – participants are reminded to not disclose any of the other participants' information.
    - individual interview – as much as possible held in a private area
    - covert observation
        - if passively observing the participant; could the individual have an expectation of privacy (e.g., chat room for breast cancer patients)
    - Will participants feel comfortable providing the information in this manner?
    - Will the researcher collect information from primary participants about a third-party individual that is considered private (e.g., mental illness, substance abuse in family)? If yes, informed consent should be obtained from the third-party.
    - What are the cultural norms of the proposed participant population? Some cultures are more private than others.
    - What are the ages of the proposed participant population? There may be age differences in privacy preferences (e.g., teenagers less forthcoming than older adults)
- Do you plan to share data collected for research with individuals outside this institution?
- Do you plan to maintain identifiable data or specimens for future use?

Some more well-known laws/measures that may protect participants' privacy and the confidentiality of their data include, for example, the following:

- Health Insurance Portability and Accountability Act (HIPAA) (some provisions of which are referred to as the "Privacy Rule"), relating generally to health information. Refer to the IRB's Guidance for Accessing Health Data Including Protected Health Information (PHI)
- General Data Protection Regulation (GDPR), a regulation of the European Union (EU) pertaining to generally to data collected from or about residents of the EU/European Economic Area (EEA). Visit the IRB's page on GDPR to learn more.

- Certificates of Confidentiality, protecting researchers from legal requests for participants' identifiable information
- Family Educational Rights and Privacy Act (FERPA), which protects the students' educational records; see Chapman's FERPA page for additional information.

Chapman investigators must adhere to the university's security standards corresponding to the risk classification of the data.

References:

University of Pittsburgh. (2021, May 6). *Privacy and confidentiality for research participants*. www.hrpo.pitt.edu. https://www.hrpo.pitt.edu/privacy-and-confidentiality-research-participants

Privacy, Confidentiality, and Anonymity in Human Participants Research. (n.d.). hrpp.usc.edu. https://hrpp.usc.edu/irb/privacy-confidentiality-and-anonymity-in-human-participants-research/

Privacy and Confidentiality - IRB. (2019). ucdavis.edu. https://irb.ucdavis.edu/project-guidance/privacy-and-confidentiality/

Confidentiality, Privacy and Information Security in Human Research | FSU Office of Research. (2025). fsu.edu. https://www.research.fsu.edu/research-offices/ohsp/investigator-resources/confidentiality-privacy-and-information-security-in-human-research/

University of Virginia. (2024). *Protecting Confidentiality | Human Research Protection Program (HRPP)*. virginia.edu. https://hrpp.research.virginia.edu/teams/irb-sbs/researcher-guide-irb-sbs/protecting-confidentiality

Guidance: Protecting Participant Privacy and Maintaining Confidentiality of Data. (n.d.). https://research-compliance.umich.edu/sites/default/files/resource-download/privacy_confidentiality_hrppguidance_final.pdf

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