Anonymity, Confidentiality, and Privacy in Human Subjects Research

“Anonymity,” “confidentiality,” and “privacy” are three terms frequently used, and misunderstood, in human subjects research. The UNH Institutional Review Board (IRB) for the Protection of Human Subjects in Research uses these terms as follows:

- **Anonymity:** No identifiers (e.g., name, address, telephone number) are collected that link information/records/samples to the individual from whom they were obtained.

  Data collected in person (e.g., via interviews, videorecording) cannot be described as anonymous, and the existence of a list of codes and associated identifiers (e.g., names) means that data are NOT anonymous. Further, if a combination of variables collected are likely to identify unique individuals (e.g., a 52 year old female Asian senior at UNH), particularly in small, bounded samples, the data should not be described as anonymous. If data are not anonymous, participation in the research may present risk if there is a breach of confidentiality and identifiable information is released without subjects’ permission.

- **Confidentiality:** The treatment of information (data) disclosed in a trust relationship and with the expectation that it will not be divulged without permission to others in ways inconsistent with the understanding of the original disclosure.

  Confidentiality is an agreement between parties made via the consent process. Researchers must keep subjects’ contributions to the research confidential unless subjects have agreed otherwise (preferably in writing). Researchers, however, cannot guarantee absolute/complete confidentiality and must inform subjects of this. For example, in the case of a complaint, the IRB may have to review data. Further, researchers have to comply with applicable mandatory reporting laws (see the IRB guidance, [Information Individuals in New Hampshire are Legally Required to Report](#)), court orders, and/or other legal actions. Finally, transmission of data via the Internet (e.g., surveys conducted via the Web or email, interviews conducted via Skype), presents a low risk of a breach of confidentiality. This may be minimized by encrypting transmission of data.

- **Privacy:** An individual’s control over the extent, timing, and circumstances of sharing him/herself (physically, behaviorally, or intellectually) with others.

  Researchers must protect subjects’ privacy. Researchers must safeguard subjects’ privacy during recruitment for the study and during data collection. Data must be stored securely and in a form that prevents, where possible, the identification of individuals.

Privacy pertains to people whereas confidentiality pertains to data; privacy is a right that can be violated whereas confidentiality is an agreement that can be broken.
Best practices for researchers:
1. When recruiting, supply potential subjects with information about the study that those subjects can then forward to other people who may be interested in participating in a study. Researchers should NOT obtain from individuals names and/or contact information of other potential subjects without the others’ permission.

2. Use the informed consent process to brief subjects about the measures in place in the study to ensure confidentiality of their data. Such information should include:
   a. Who will have access to the data;
   b. Where and how data will be stored;
   c. How data/results will be reported (e.g., in aggregate, using pseudonyms); and,
   d. How results may be used (e.g., in reports, publications, presentations).

Further, explain the disposition of any recordings at the end of the study. If recordings may be used in future research, clearly explain such use in the consent form. If researchers plan to use recordings in public fora, such as in presentations or posting them on websites, obtain from subjects explicit consent for such use, and explain whether subjects will be identifiable and/or identified.

3. Gather only data necessary to answer the research question(s).

4. Web-based surveys (e.g., using Qualtrics) can facilitate anonymous data collection. In order to characterize participation in a Web-based survey as anonymous, however, researchers must disable the feature allowing the collection of IP (internet protocol) addresses (which may identify the computer user) in addition to not collecting any identifying information, such as information (gender, age, race, work-site, etc.) sufficient to identify unique individuals, particularly in small, bounded samples.

5. Treat all human subjects data and associated study documentation (e.g., list of subject codes) as confidential, and code and store in a secure manner (i.e., a file or cabinet with a combination lock, or a password-protected, encrypted computer).

6. If human subjects data are to be collected and/or stored electronically:
   a. Back up all electronic data frequently to a secure source.
   b. Transfer data and/or files between electronic devices, individuals, offices and/or institutions in a secure manner. Some data transfers may require special procedures (e.g., encryption).
   c. Never store data solely on portable media, such as electronic recording devices (e.g., cell phones, tablets), thumbdrives, or laptops. While data may be collected and/or transferred using portable devices, transfer such data as soon as possible to a desktop computer and/or back up the data to secure servers or secure cloud storage.
   d. Limit access to authorized and identified persons.
   e. Maintain a distinct separation of data from identifiers. If identifiers are necessary for editing, analysis, etc., delete them from data as soon as possible.
   f. Since complete data raise the possibility that some individuals might be identified if a sufficiently detailed question is asked of the data, take particular care to assemble the information to prevent such identification. Do not store responses from uniquely identifiable individuals, groups, or companies in a manner that allows identification by source.
g. Once data have been transferred to an electronic medium from paper data collection forms and verified, destroy original paper forms (e.g., by shredding), unless keeping original paper copies is required (e.g., by professional standards).

7. Limit access to hard copy human subjects data to authorized personnel, and institute a sign-out, sign-in procedure.

8. If recordings (i.e., video or audio) are transcribed, destroy the recordings as soon as the accuracy and completeness of the transcriptions have been verified. If using recordings as primary data sources and not transcribing them, take extra precautions to secure the recordings, particularly those recordings containing identifiers. Further, retain such recordings at the end of the study as research data (see #11).

9. If conducting analyses on subsamples, ensure that the smaller group size does not lead to unintentional disclosures.

10. Be aware that reporting results of human subjects research places a special burden on researchers, whether the report is in the form of a research article/paper, report, presentation, news release, or newspaper story. The following factors must be impressed on all researchers involved in a study:
    a. There is no statute of limitations on the confidentiality of subject information. All researchers must agree to refrain from identifying subjects where subjects have not otherwise given permission.
    b. Direct quotes and descriptive information may reveal the identity of subjects.
    c. Incidental identification of a subject may well occur under any one of the circumstances listed below, or in any combination thereof:
       i. The study involves a small sample size.
       ii. The total population from which the sample is drawn is small.
       iii. The general characteristics of the aggregate population are stated directly or indirectly. Size of town, community character (e.g., industrial, agricultural center, suburban, education community, etc.), and general location may be sufficient to identify the town, and, possibly, research subjects.
       iv. Any confluence of characteristics of family structure (size, sex distribution of children, ages, marital evolution), details of personal characteristics, or expressions of individuality which together would permit statistical identification.

11. Do not destroy data at the end of a study, but rather de-identify them and store them securely. Further, researchers need to comply with the UNH policy on the Ownership, Management, and Sharing of Research Data, including for the retention of research data.

For more information on the UNH Institutional Review Board or institutional requirements regarding research involving human subjects, please contact Research Integrity Services staff (Julie Simpson, 603/862-2003, or Theresa Cherouvis, 603/862-3536). Additional materials are available on the IRB webpage at http://unh.edu/research/human-subjects.