University of Wisconsin-Oshkosh
Institutional Review Board (IRB)

STANDARD OPERATING PROCEDURES (SOP)	
SOP Number: 13 Effective Date: 12/7/2021 Last IRB Review: 12/7/2021 Last Updated: 12/7/2021 Prepared By: A. Miron, K. Schill	**Title:** **Anonymity versus Confidentiality Considerations**

When conducting research and collecting data, researchers often claim that the research will be conducted anonymously or confidentially. There are important differences between the two terms and these differences have important implications for the participants, their protection from harm, and for participants' willingness to participate in the project. Some of the risks associated with the distinction between anonymous and confidential may come from revealing certain information, e.g., medical records, beliefs, or school transcripts.

Anonymity

A project or data collection is anonymous if:

1. The project does not collect any unique identifiers of individual subjects (e.g., name, address, email address, SS#, phone number, etc.) AND;
2. The project does not collect any identifiers that combined would allow an individual to be identified. For example, age alone is not a unique identifier, but the combination of demographics like age, gender, major, race, honors program participation, and number of semesters at UW Oshkosh could allow a participant to be identified.

A **"strictly anonymous"** study design is one in which it is impossible to trace data or information back to the research subject from whom it was obtained. In other words, the data **cannot** be identified to any research participant, not even by the researcher. Please see the IRB's Identifiers Guidance.

Considerations:

- A study in which the researcher creates a code linking the participant's identity to a pseudonym or a number CANNOT be classified as an anonymous study, as the identity of the subject can be traced back to the data.
- A study in which a researcher collects participants' signatures on a written consent form CANNOT be classified as anonymous even when the consent form is being separated from the data that the participant provides.
- As a general rule, online surveys (Qualtrics, SurveyMonkey, Zoomerang, etc.) CAN BE classified as anonymous. For instance, both Qualtrics and Survey Monkey have an option that can be set to not collect IP (Internet Protocol) addresses. The researchers must assure the IRB in writing the protocol that the process does not collect IP addresses which could identify the computer user. However, data collected using other crowdsourcing platforms such as Amazon Mechanical Turk (Mturk) are not considered

anonymous because researchers will have access to participants' Mturk worker ID numbers. Moreover, online studies in which researcher first collect participant signatures on a written consent document before the participant completes the study online are not considered anonymous.

In sum, if data is in any way identifiable or can be connected to the participant (directly or indirectly, even if only by the researchers), the data collection process cannot make the claim of being anonymous.

Confidentiality

Confidential research participation means that the data from the research subject(s) **can** potentially be identified or linked to a particular individual. Please see IRB SOP #15: *Guidance for Protecting Privacy and Confidentiality* for additional information about protecting confidentiality of identifiable private information:

- Thus, **any** data collected face-to-face is automatically considered in the category of being "confidential" as opposed to "anonymous." This is true even when the researcher assigns a numerical code to the participant and this number cannot be traced back to the subject because the researchers themselves know who provided the data.
- Federal regulations require the IRB to ensure the research contains adequate provisions to maintain the confidentiality of research data, when appropriate. Confidentiality procedures should consider the sensitivity of information collected and the risks associated with a breach of confidentiality. The IRB may consider a waiver of the signature requirement, if that would serve to protect the identity of participants.

Considerations:

- While data collection may be confidential (e.g., researcher knows who participated in the study), it is possible to **de-identify** these data. This happens when a researcher aggregates individual responses into groups (race, age, experimental and control groups) and report only means and standard deviations. This procedure of data deidentification works as long as there is not an n = 1 among the demographics (e.g., only 1 female African American student). This makes the **processed data** (the final data file) anonymous, but it would be incorrect to say the **data collection** method is anonymous.
- In general, participants are at greater risk when their responses can be tied to their identity. **Typically, it is best to collect only the data that is necessary to achieve the specific research goals.** In addition, extra data protection measures need to be taken when a study involved confidential participation:
    a. The researcher must secure the collected data (e.g., samples, audio or video recordings, and information) in a locked file cabinet or secured electronic environment, to which only the researcher and/or other approved trained assistants have access.
    b. If the researcher assigns each participant a "code" that connects them to the data, then he/she must store the code in a locked file cabinet, or a secured

electronic location separate from the data/date file. Electronic data safeguarding measures include using current IT security standards: e.g., user passwords and authentication, firewalls, anti-virus programs, encryption, isolation from networks, etc.

c. The researcher must inform the research participants of these measures to ensure confidentiality. This information should be included within the written consent form they sign. Further, the consent document should include the plans for destroying the original data at some reasonable point after the research project is completed, typically five years after publication or immediately after transcriptions are done.
d. There are ethical or legal limits to confidentiality, for example, when a researcher obtains information subject to mandatory reporting, such as evidence of child abuse. If it is probable that information subject to mandatory reporting may be collected during the study, a researcher should state these exceptions to confidentiality in the consent form.
e. Research involving information about illegal behaviors may require a federal Certificate of Confidentiality (CoC), which protects against disclosure to law enforcement agencies and prevents records from being subpoenaed. Research that requires a Certificate of Confidentiality will also require additional information in the consent form. **If the investigator seeks to obtain identifying information of a sensitive nature from research subjects, and the disclosure of such information could harm the subjects as described above, the PI may wish to apply to the government for a CoC.** The investigator should indicate in the application to the IRB that he or she will seek a CoC after the IRB has approved the application. Some grants agencies automatically issue the COC at the time of award: https://grants.nih.gov/policy/humansubjects/coc.htm
f. Some research may also require compliance with additional federal or state laws governing confidentiality where applicable, e.g., medical records (HIPAA) (please see the IRB HIPAA Quick Reference Guide) or academic records (FERPA) (see *IRB SOP #10: Guidance on FERPA and the Use of Student Records for Research*.

This resource was developed in part using material from:

1) https://www.roanoke.edu/inside/a-z_index/institutional_review_board/policies/confidentiality_vs_anonymity
2) https://www.washington.edu/research/hsd/special-topics/subject-privacy-confidentiality-and-identifiable-data/
3) https://www.ndsu.edu/fileadmin/research/_Forms/Res_Int/Irb/Sops/8.2PrivacyandConfidentiality.pdf
4) https://www.cmc.edu/sites/default/files/irb/IRB%20anonymous%20vs.%20confidential.pdf