**IRB Tipsheet: Guidance for Protecting Participants when Studying Sensitive Topics and Illegal Behavior**

# **Overview**

If your research involves asking participants survey or interview questions about sensitive topics and/or illegal behavior or exposing them to information about sensitive topics, likely you will need to put additional safeguards in place to protect participants from harm and get IRB approval for your study (see suggestions below).

Examples of research topics that may be considered sensitive and emotionally triggering include, but are not limited to: adverse childhood experiences, mental/physical health illnesses/disorders, discrimination, substance abuse, illegal behavior, war/violence, death, sexual assault/abuse/discrimination1, and other traumatic experiences.

# **I. IRB Submission Considerations**

Please plan to submit research on sensitive topics to IRB well in advance of the planned data collection start date because these protocols may end up needing to go through more extensive revisions or full IRB board review.

This list below highlights the appropriate steps you should take for submitting protocols like these. However, please note that not all of these recommendations will be suitable for your research. Review and apply those that are most applicable.

## **Sensitive Topics in General**

These considerations will likely be applicable to all human subjects research focusing on sensitive topics and illegal behavior, and therefore should be addressed in all submissions:

1. Include detailed information about these topics in the consent form so participants know what sensitive topics are being covered in case any might be particularly distressing to them.
2. Include information about potential risks of negative emotional reactions in the consent form.
3. Make clear in the consent that participants can refuse to answer any questions.
4. Include in the consent and/or debriefing form contact info to relevant mental health/support resources (e.g., [crisis hotline, support groups](https://www.uwlax.edu/globalassets/offices-services/grants/debriefing-form---resources-2023.docx)) in case participants have a negative emotional reaction.
5. Include a data security confidentiality statement in the consent form that warns about potential breach of confidentiality being a risk if data are not anonymous. (See example confidentiality statement on IRB website.)
6. If including a scale that is a screening tool that includes scoring information (e.g., mental health diagnostic screeners), explicitly note that the scoring information will not be provided to the participants. Also note whether the participants will be told that these questions are a screening tool. It may be better not to tell participants this so that they don’t attempt to diagnose themselves while participating in your study.

## **Asking about Personal Illegal Behavior**

First, consider whether you really need to ask questions about illegal activity for the purposes of testing your hypotheses/research questions. If you do, then apply these precautions:

1. The consent form must include a statement on the risk related to the disclosure of illegal activity:
   * For example: I will be asked to share details of my personal drinking behavior that could include disclosing illegal activity if I am under 21. If I do provide information about illegal activity, the researchers will do their best to ensure the data are kept confidential; however, while very unlikely, in the event of a warrant or subpoena for research data, the researcher may not be able to guarantee the confidentiality of participants’ data on any illegal alcohol use.
2. If possible, ask questions in such a way that specific illegal behavior is not known.
   * For example: instead of asking if they struggled with illegal substance/drug abuse, ask if they have struggled with substance/drug abuse (which could be legal substances)
3. If possible, refrain from asking about the specific time/place of illegal behavior.
   * For example: Instead of asking whether they smoked marijuana in the past seven days, ask them if they smoked it in the past year or at all.
4. If asking about drinking among a population that includes those under and over 21, consider not collecting information about the participant’s age so that they don’t reveal underage drinking. Or restrict your sample to those 21 and over.
5. Consider whether it would be better to not gather participants’ names on consent forms if this is the only document that ties them to a study on illegal activity.
   * If it would be better not to have them sign, request a waiver of signed consent in your IRB narrative (#4) and fill out an Attachment D form.

## **Ensure Confidentiality is Maintained**

Take steps to maintain confidentiality of the data and protect participants’ privacy. This may include:

1. If using Qualtrics, double check that the “anonymous” button is checked before and after you publish an online survey.
   * However, in the consent form, don’t assure participant’s anonymity if using a Qualtrics study, instead promise them confidentiality. It may be possible for Qualtrics to access IP addresses even if the survey is marked “anonymous”.
2. Use random number codes/pseudonyms rather than names or other identifying information (birthdates/phone numbers/emails/student IDs) when collecting data.
3. Don’t audio/video record participants. If you must record them, transcribe recordings promptly without identifiers and destroy recordings as soon as possible.
4. Exclude questions that if answered a certain way could identify participants.
   * For example, if very detailed demographics are collected, by combining all the demographic data together, a person could be identified (e.g., if there is only one Korean-American transgender student on the UWL campus). Only ask for demographics at the level of detail that you really need. You could specifically tell participants that the demographic questions have limited response options to avoid participants from minoritized identities inadvertently identifying themselves in their responses.
   * You could also instead have demographic data collected on a separate survey/data response sheet and not linked to participant’s other data.
5. If using the extra credit tool Sona to recruit participants, don’t directly connect a Qualtrics survey to Sona – that produces a code that can identify participants.
6. If gathering identifying information to award gift cards to participants, make sure this identifying information is not connected to their data (e.g., record it in a separate survey or on a separate document).
7. Store hard copies of data in locked cabinets/rooms and electronic data on encrypted computers/servers and password protected devices.
8. Store data, master code lists, and signed consent forms in separate secure locations.
9. Limit access to data to as few individuals as possible and transfer data between researchers securely.