BUFFALO STATE
The State University of New York

Institutional Review Board
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SOCIALLY SENSITIVE RESEARCH

Socially sensitive research includes studies in which there are potential consequences or implications, either directly for the participants in the research or for the class of individuals represented by the research. Sensitive topics are those that either seem threatening or contain an element of risk in some way; hence, such research involves potential costs and consequent problems for both the participants and researchers. Other sensitive topics include areas which are private, stressful or sacred, or potentially expose incriminating information.

Risks: In this kind of research, risks may often include:

- Loss of confidentiality about the identity of the volunteers
- Loss of confidentiality about the information given by the volunteers
- Triggering concerns within volunteer-respondents (e.g., emotional reactions or needs)
- Triggering concerns about social, stigmatizing, or physical harm to volunteers (e.g., assault by abusing partners or legal action by authorities) if subject participation in the study became known
- In some research (e.g., about fetal alcohol syndrome), the people at risk include not only the participants in the research, but third parties (e.g., the mothers) as well.

Confidentiality: One of the most important risks in socially sensitive research is the effect of a breach of confidentiality. The researcher must make every effort to try to ensure confidentiality; we suggest relying on anonymity whenever possible.

Anonymity means that no one, not even the investigator, can identify an individual participant after the data are collected. Simply eliminating names and other obvious identifiers does not guarantee anonymity; demographic information can sometimes identify participants as well, especially if the sample size is not large. Any information or pattern of information that can uniquely identify an individual eliminates anonymity.

When anonymity is not feasible, then the researcher must demonstrate to the IRB how confidentiality can be assured. Depending on the sensitivity of the subject matter, extra care should be taken to ensure that participants could not be identified. Sometimes, coding schemes should be used to minimize the risk of a confidentiality breach.

Emotional Risks: To minimize the risk of emotional distress triggered by the research itself, the researcher must take steps before, during, and after the intervention with the participant:

- to assess the emotional impact of the material
- to assess the emotional state of each participant
- to address any emotional reaction which might take place

Procedures for assessing and minimizing emotional reactions include:

- pilot testing research materials
- extended listening
- ventilating discussion
- referral to counseling services (cooperation of counseling services must be obtained before approving the research).

Social Risks: If the research concerns illegal behavior (e.g., a study of HIV and risk factors among prostitutes), the researcher may need to have the cooperation of local legal authorities or a Federal Certificate of Confidentiality.

If there is a risk of triggering retribution by others, such as violence by abusing partners, the researcher must ensure that no individual participants can be identified. Risk to the community must be minimized, often by researchers and the community agreeing about publication (e.g., whether to identify the community).

Benefits: Researchers should also maximize benefits of the research to each volunteer and community. They must ensure availability of services to the volunteers. For a survey of fetal alcohol syndrome, for instance, researchers should link to established, or help establish, prevention and treatment services. At the very minimum, participants should be provided with sources of help and support available in the community.

Coercion: Research involving emotionally vulnerable participants should avoid coercion to participate by caregivers. Many patients who are dependent on caregivers' help may feel that refusing to take part in research will lead to loss of the care they need, in spite of the written "non-coercion disclaimer" in consent forms. One way to avoid the problem is to emphasize repeatedly the freedom to refuse participation. Another is to have at least the consent, and sometimes the research as well, administered by people other than the caregivers.