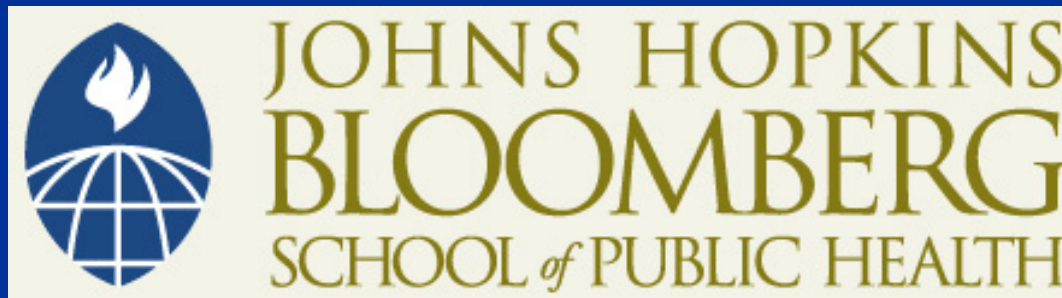


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Ethical Issues in Qualitative Research

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Overview

- Ethical principles guiding public health research are built on a foundation of medical ethics, developed in the first instance to regulate the conduct of clinical research.
- The application of medical research ethics to qualitative research can be awkward at times.
- We will practice how to apply ethical principles to a range of qualitative research scenarios.

Qualitative Methods

- Observation
 - Structured
 - Participant
- In-depth interviews
- Focus Group Discussions

Overarching Ethical Principles

All researchers are responsible for ensuring that participants

- Are well-informed about the purpose of the research they are being asked to participate in
- Understand the risks they may face as a result of being part of the research
- Understand the benefits that might accrue to them as a result of participating
- Feel free to make an independent decision without fear of negative consequences

Issues in Qualitative Research

- Protection of participants through the informed consent process favors formalized interaction between researcher and participant.
- Strength of qualitative research methods often lies in the informality of the communication as well as the iterative nature of the research process.
- How can we reconcile these two conflicting dynamics?

Structured Observation

- You are interested in documenting patterns of social activity at different types of bars in preparation for developing an intervention to reduce sexual risk taking associated with drinking. You propose to do an inventory of all legal bars in a given neighborhood and start visiting them. You will visit bars at different hours of the day and record your observations (how many people are there, whether there are sex workers present, what people are drinking, general observations of the environment). You record these observations on a form and plan to eventually use these data in your publication.
 - Who are the research participants?
 - What are the risks?
 - How will you minimize the risks?
 - Who needs to provide informed consent?
 - As an IRB member, what are your main concerns?

Participant Observation

- You go to the bar and have a drink! You make friends with bar patrons and start hanging out there on a regular basis. You talk informally to bar patrons about their drinking patterns and sexual lives. You take field notes about these conversations and include details about these individuals (without identifying them). You plan to use these data in your publication.
 - Who are the study participants? What are your obligations to offer an informed consent process to them?
 - What information would you provide? When?
 - What are the risks to participants?
 - How would you minimize the risks?
 - As an IRB member, what are your concerns?

Guidance

- The obligation to inform people that they are part of a research project is universal, no matter what your methods!
- Always be honest about who you are, what your research is about, why you want to talk, and what you will do with the information.
- Depending on your methods, written informed consent may not always be necessary and may, in fact, negatively impact the quality of your research. Always consult the IRB for guidance and work with them to come to mutually agreeable solutions to protect the participants as well as the integrity of your research process.

Guidance

- Establish clear procedures that reduce risk and maximize confidentiality (GQP):
 - Ensure your field notes and transcripts do not contain personal identifiers.
 - Keep raw and processed data locked and/or password protected
 - Share data only with those who are part of the study team (investigators) and who have received research ethics training
 - If you are supervising a team to collect data, conduct thorough ethics training of EVERYONE.
 - Establish clear chain of custody procedures to ensure data is not diverted or lost.
 - Conduct regular audits of yourself and your team to ensure compliance

In-depth Interview

- You are doing a study on perceptions of HIV testing in South Africa. You find that many young women you interview bring up stories of sexual trauma they have experienced, including rape. There are several cases in which the interview becomes very upsetting for both the participants and the interviewers. You have already received IRB approval and your informed consent form talks about the risk of feeling uncomfortable with some of the questions. But the responses are more overwhelming than you expected.
 - What are your obligations to the participants in terms of reducing harm related to anxiety during the interview?
 - Should you stop the interviews and revise your consent form?
 - Should you report any of this to the IRB?
 - As an IRB member, what are your concerns about in-depth interviews?

Focus Group Discussion

- You are conducting a series of focus group discussions with women who have survived abusive relationships. You are interested in asking these women to describe the types of abuse they survived and how they made the decision to leave the abusive relationship. Each group will have about 5 women.
 - What possible risks may occur to these women as a result of participating in your study?
 - How could you help minimize those risks?
 - As an IRB, what are your concerns about focus group discussions in general and this one in particular?

Special Issues

- You have interviewed VCT clinic staff members. The clinic has low uptake of testing and a lot of staffing problems. The hospital administrator calls you into his office and wants to know the results of your interviews. You don't want to violate participants' confidentiality but you also think the administrator should have some feedback from the research.
 - How do you balance the two responsibilities?
 - As an IRB member, what are your concerns about how the results of research are fed back to participants and other stakeholders?

Guidance

- Talking can stir emotions, this is not necessarily bad or risky, though could be in extreme cases.
- Plan ahead by providing adequate referral services to participants and have a crisis management plan in place for participants and staff members.
- When in doubt, stop data collection and make a report to the IRB and ask for guidance.

Guidance

- FGDs are typically best used for topics that are less sensitive, where loss of confidentiality is not a substantial risk.
- Dissemination of qualitative research results is important. Make every effort to report results in a way that protects participant confidentiality and disallows retribution. This requires conducting good groundwork with authorities before beginning fieldwork.