Ethical issues

Ethical Considerations

- Confidentiality
- Informed consent
- Trust
- Power relations
- How to handle respondents asking for professional advice

Goal of this session

To become familiar with informed consent

VERY important

- If possible get written informed consent from the people you are interviewing
- Important – especially if you will want to publish the results in a scientific journal
- A template for informed consent forms made by WHO

BASIC elements in the informed consent form for "research ethics with human subjects"

- inform them about your research project – the purpose
- inform them about anonymity
- tell them what you expect to use the results for
- have in WRITING that they can withdraw from the interview/study at any time
- You CAN (but not necessary) tell them that you can send them a copy of your report (I suggest you only talk about this IF THEY ASK – otherwise it could be a big expense)

IF YOU CANT GET WRITTEN INFORMED CONSENT

- then as an alternative you must get ORAL INFORMED CONSENT which you make sure you TAPE RECORD. The information is the same as above

Research Ethics Review Committee (WHO ERC)

- Informed Consent Form Template for Qualitative studies
  - Available on the net: http://www.who.int/rpc/research_ethics/informed_consent/en/

Notes to Researchers:

- these are templates developed by WHO ERC to assist in the design of informed consent forms (ICF). It is important that researchers adapt their own ICFs to the outline & requirements of their particular study.
- **The logo of the Institution must be used on the ICF and not the WHO logo**.

- The informed consent form consists of two parts:
  - the information sheet
  - the consent certificate

- The templates are long because they contain guidance & explanations which are for you
- you will not include all this text in the informed consent forms that you develop & provide to participants in your research.

- The templates include examples of key questions that may be asked at the end of each section, that could ensure the understanding of the information
- These are just examples, & suggestions, & the investigators will have to modify the questions depending upon their study.
- In these templates:
    - square brackets indicate where specific information is to be inserted
    - bold lettering indicates sections or wording which should be included
    - standard lettering is used for explanations to researchers only & must not be included in your consent forms. The explanation is provided in black, & examples are provided in red in italics. Suggested questions to elucidate understanding are given in black in italics.

Exercises

- You are volunteering or working in a non research setting (e.g., at a rape crisis center or at a restaurant) and in the course of your work decide that this would be a good place to collect qualitative data through informal interviews and observations. You do not want to tell people about your study because you would be speaking with them and observing them any way. What are the ethical implications of this situation?

- You are meeting with scholars in another country where you are planning to conduct research interviews. The experts from that country advocate hiding the tape recorder during the interviews to avoid making the participants nervous. There is no Human Subjects Review Board in that country. What do you do?

- You are evaluating an educational program for preschool children, a program that you think is useful, if not perfect. In the process of conducting your study you learn that the directors of the program are falsifying rates of completion to maintain their levels of funding. If this information were to be come public, the program would be forced to shut down. What do you do with this "guilty knowledge?"

Questions