

Research Ethics

Two Week Online Faculty Development Programme (FDP) on
“Engendering Research with Feminist
Research Methods”

<https://meet.google.com/tnw-bbue-exv>

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Realising the Need for Ethics in Research

- ▶ Started with biomedical Research.
- ▶ Nuremberg trials
- ▶ Western society - heterogenous, but egalitarian society
- ▶ Ours, hierarchical society

Some examples from our everyday life:

- ▶ Unethical use of ignorant people as research subjects:
 - ▶ mobile sim,
 - ▶ membership to different websites,
 - ▶ data on banks,
 - ▶ credit cards,
- ▶ It is not that only the people who lack complete access to education is to be understood as ignorant, all of us, who do not feel the necessity to read the instructions and terms and conditions printed in very small fonts in every product that we purchase - are negligent, but since we sign, we are cannot claim that we are cheated.

Hierarchical Relationships:

All of us have accustomed to power, and we always agree that certain relationship has to be like this.

- ▶ Teacher versus Students,
- ▶ Rich versus poor
- ▶ employer versus employee

- ▶ We don't think of an egalitarian possibility - can a student question the integrity of a teacher? Will the teacher get offended or is it the responsibility of the teacher to explain.

What kind of a society we are?

- ▶ Master Slave Relationship.
- ▶ We are basically unethical society.
- ▶ We may say murder is wrong, but the moment we come to know that murder is due to an inter-caste marriage, we shut our mouth.
- ▶ We would keep our home very neat and clean, but we will throw our garbage just outside the compound wall.
- ▶ We will not insult the person who is polluting, but we will treat the person who cleans it with utter disgust.
- ▶ we may not want to work as a manual scavenger, but we will say, they should be paid more. we will never want demand manual scavenging to be abolished.

Below is an example of an Informed Consent form. Informed consents should include the information listed below.

- ▶ Informed Consent
- ▶ Title of Research:
- ▶ Principle Investigator, Affiliation and Contact Information:

- ▶ Additional Investigators and Affiliations:

- ▶ Institutional Contact:

1. Introduction and Purpose of the Study

- ▶ Include a brief overview of the study on a level of understanding for the person who will be signing the form. Remember that the general population might not understand what you consider basic terminology. A general rule is to keep the wording at no more than an 8th grade reading level.

2. Description of the Research Include a description of what participation in the study entails.

- ▶ Example: “When you enter into the program, you will be asked to complete two questionnaires. You will then be asked to participate (EXPLAIN INTERVENTION IN BASIC TERMS). After you have completed the (intervention), you will be asked to complete two more questionnaires.

3. Subject Participation:

Give an overview of what participant characteristics are needed for the study.

- ▶ Example: We estimate that 20 participants who (describe population) will enroll in this study. Participants must have (describe inclusion criteria, for example: participants has some motor ability in both hands and can verbally communicate). Your participation will involve one visit, approximately 50 minutes in length.

4. Potential Risks and Discomforts

- ▶ In this section include any potential risk or discomforts, and how those risks will be addressed if they arise (call 911, refer to mental health clinic, etc.). If you believe there are no risks involved, since there is never a guarantee, state that there are “no known risks”.

5. Potential Benefits:

Include a statement about potential benefits for participating in the study.

- ▶ Example: People who participate in this study may have a better understanding of additional treatment methods that enable individuals to experience and increase their overall sense of wellbeing.

6. Confidentiality:

In this section let the participant know the level of identity protection of any personal information collected for this study. Will their identity be fully protected, and if so how, if not, then to what level and what will be publicly available?

- ▶ Example: All information taken from the study will be coded to protect each subject's name. No names or other identifying information will be used when discussing or reporting data. The investigator(s) will safely keep all files and data collected in a secured locked cabinet in the principal investigators office. Once the data has been fully analyzed it will be destroyed.

- ▶ Example: Your responses are completely anonymous. No personal identifying information or IP addresses will be collected. Data will be aggregated via the Qualtrics reporting function. Quantitative results will be shared with the Chairperson and the faculty in the academic unit. Qualitative results will be shared with the Chairperson and the Provost's Office.

Example:

- ▶ I would like to interview you “on the record” so that I can identify you in publications resulting from this research. However, if you wish to remain anonymous, I will keep your name separate from your words; I will not use your name in any quotations or reports of my findings; I will use a pseudonym of your choosing; and I will omit or obscure any identifying details.
- ▶ If the research will be collecting audio or video recordings, there must be a statement explaining how the recording will be handled and at what point destroyed.
- ▶ Example: Once audio recordings are coded and transcribed they will be destroyed.

Example:

- ▶ I will store audio recordings and any electronic or printed transcripts in encrypted files or in a locked, secure location for five years after the publication of this research, after which, all files will be destroyed.

Authorization

- ▶ Example: By signing this form, you authorize the use and disclosure of the following information for this research:
- ▶ Example: I authorize the use of my records, any observations, and findings found during the course of this study for education, publication and/or presentation.

7. Compensation

- ▶ In some research studies participants will receive some type of compensation. This could be in the form of money, gift card, or items. In this area you must state if there is, or isn't, compensation. If so, explain in what form and when it will be issued.
- ▶ Example: Subjects will not be compensated for participation in this study. Or: Each participant will receive \$10.00 at the conclusion of the study.

8. Voluntary Participation and Authorization

- ▶ Participants need to be made aware that they do not have to participate in the study, and that it is fully voluntary. If they decide not to participate they must be informed that it will not affect any relationships they have with the researcher and/or facility in which it is administered. Example: Your decision to participate in this study is complete voluntary. If you decide to not participate in this study, it will not affect the care, services, or benefits to which you are entitled.

9. Withdrawal from the Study and/or Withdrawal of Authorization

- ▶ Participants also need to know that they can withdraw at any point if they choose not to continue. In this section you can put in a withdrawal process, such as they need to inform the research(s) in writing. Additionally, if appropriate to the study, if data has already been collected, they can be informed that anything collected prior to withdrawal will be included in the study. Example: If you decide to participate in this study, you may withdraw from your participation at any time without penalty.

10. Cost/Reimbursements

- ▶ Here you will let the participant know
- ▶ if there will be any fees attached to their inclusion in the study.
- ▶ Will they have to pay for the materials, supplies, transportation, etc?
- ▶ Example: There is no cost for participating in this study.
- ▶ Any medical expenses resulting from participation in this study will not be reimbursed by the investigators.

I voluntarily agree to participate in this research program

- ▶ Yes
- ▶ No
- ▶ I understand that I will be given a copy of this signed Consent Form.
- ▶ Name of Participant (print):
- ▶ Signature: Date:
- ▶ Name of Witness (print):
- ▶ Signature: Date:
- ▶ Person Obtaining Consent:
- ▶ Signature: Date: Note: A copy of the signed, dated consent form must be kept by the Principle Investigator(s) and a copy must be given to the participant.