

Research Ethics, Consent and Research Steps

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Research Ethics

- **Norms for conduct** that distinguish between acceptable and unacceptable behavior.
- Ethical norms are so **ubiquitous** that one might be tempted to regard them as **simple commonsense**.

Research Ethics Aim

- Promote the **aims of research** (e.g. knowledge, truth, and minimizes error) - prohibitions against fabricating, falsifying, or misrepresenting research data.
- Promote the **values that are essential to collaborative work** (such as trust, accountability, mutual respect, and fairness).
- Help to **build public support** for research. People are more likely to fund a research project if they can trust the quality and integrity of research
- NB: Ethical lapses in research can significantly harm human and animal subjects, students, and the public

Principles of research ethics

- **Respect for persons:** Right of people to decide on what on what happens to them
- **Beneficence:** protect participants well being
- **Justice:** fair distribution of benefits and burdens
- **Privacy and confidentiality:** protect personal data

RESPECT FOR PERSONS: Two main guiding principles

AUTONOMY

- People must be (or must be put) in a position to make decisions concerning their actions and wellbeing. They decide for themselves.
- **Give them choice** to participate
- Put them in a **position to make the decision**
- Assumes people have the competence to make that choice - need to protect those with diminished capacity to understand the research procedures (i.e. children, mentally disabled) and prevent coercion, etc.

VOLUNTARINESS

- Emphasize participants are **free to choose to participate** and **free to leave the study**.

BENEFICENCE

Beneficence considers the balancing of benefits of research against the risks and costs

Two main guiding principles

- Do no harm: the researcher should avoid harming any participants by all means
- Maximize benefits and minimize risks: the researcher should act in a way that benefits the research participant, their community and/or the public generally

JUSTICE

- Equitable selection of individuals - Do not use always convenient populations (i.e. more accessible, more easy to convince to participate...) if the benefits won't go to them.
- All individuals given a chance to participate
- Offering/providing the treatment to the control group in an experiment

PRIVACY AND CONFIDENTIALITY

Privacy: ability of individuals to control access to their personal information. We can only record/observe what a person will allow us to!! People have the right to not answer questions.

Confidentiality: the right of people for the data they have disclosed not to be shared/accessed by other people. Do not collect information that can identify a person /do not share anonymized data.



WHAT IS
INFORMED
CONSENT



Informed Consent definition

- A **voluntary agreement** to participate in research
- It is **not** merely a form that is signed but **is a process**
- Essential before enrolling a participant and ongoing once enrolled
- The process through which researchers **respect individual autonomy**, the **fundamental ethical principle**
- It must **minimize** the possibility of **coercion or undue influence**

INFORMED CONSENT: 3 key features

- Disclosing all info to make an informed decision
- Ensuring the info is understandable
- Promoting voluntariness of decision to participate or not

Elements of Informed Consent

It should provide the following information:

- **Purpose** of the research
- **Procedures** involved in the research
- **Alternatives** to participation
- All foreseeable **risks and discomforts** to the participant (e.g. possible psychological, social, discomfort, or inconvenience)
- **Benefits** of the research to society and possibly to the individual participant

Elements of Informed Consent continue.....

- **Length of time** the participant is expected to participate
- **Person to contact** for answers to questions or in the event of a research-related injury or emergency
- Statement indicating that participation is **voluntary**
- Statement regarding the subjects' **right to confidentiality** and **right to withdraw from the study** at any time without any consequences
- **Compensation** for participation (if applicable), **snacks/refreshments** (where applicable e.g. in FGD)

Elements of Informed Consent continue.....

- Statement on how **significant new findings** will be communicated

Therefore:

- 5 Key things in a consent: **Anonymity, confidentiality, informed consent, benefits and risks**
- Inform them that they will be **recorded and the purpose** (esp. for qual)
- They should consent and sign to allow recording

Informed Consent Type: verbal or written

- **Written consent:** (e.g. FGD/SSII)
 - ✓ **For individual interviews:** form needs to be signed by the respondent
 - ✓ **For FGD:** a group representative signs on behalf of other group members
- **Verbal consent:** still contains all elements of written consent, however, the participant is verbally read the elements and verbally agrees to participate

Informed Consent process

- **Before beginning the interview:** introduce the potential participant to the survey
- **Read out** the consent to them and ask them to sign
- **Make it clear** to them that their participation in the survey is **voluntary**
- Consent must be written in **language easily understood** by the participant (or interpreted on the spot)

Research Steps for qualitative and quantitative research

Research Steps for qualitative research

- Welcoming remarks by facilitator/project lead; purpose etc
- Introductions (start with research team then participants)
- Read out the consent to participants
- Signing of the consent by an individual or group representative
- Assign identifiers (P1, P2, P3....R1,R2....) in place of actual names
- Take characteristics of the participants e.g. age, educ, marital status etc...on a sheet of paper

Research Steps for qualitative research.....

- Set some ground rules to guide the discussions (e.g. phones off, no right/wrong answer)
- Set the recorders
- Thank the participants
- Tell them whom they need to see for compensation (if any)
- Allow them to ask questions (if any)
- Leave a copy of signed consent form with participants

Research Steps for quantitative research

- Introductions led by interviewer
- Explain the purpose of the visit and the research
- Read out the consent to the participant
- Ask them for verbal/written consent
- Take GPS coordinates after you finish the interview
- Leave the respondent with a signed copy of the consent form

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