Ethical Challenges in Social Science Research

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Social Research

- It focuses on exploring, examining, and describing people and their environments, the socio-cultural, economic, and political context of complex health behaviors. (Boydell, 2007)
- It also deals with experiences of people in relation to health and illness. (ibid)



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Social Science Research

Important to help improve our societies to become better informed about how societies should be put together



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Ethical challenges in social research

- Research goal involves hypothesis testing vs. theory generation that requires appropriate design
- Methods may use quantitative vs. qualitative methods or mixed methods
- Gaining access to a target population and recruitment
- Data collection and interpretation
- Relationship between the researcher and participant



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Ethical challenges in social research

- Identifying potential participants for research particularly when research topic is sensitive may be ethically challenging (e.g. sexual harassment victims)
- -Will recruitment/identification cause harm?
- Disclosure and consent need to be viewed as dynamic rather than static
- Reporting findings should not endanger individuals or the "communities" they belong to.



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Elements of Research Ethics

- Social value
- Scientific soundness
- Post research access
- Qualifications of research team
- Protection of research participants (protection of vulnerable participants, minimizing risks, maximizing benefits, privacy protection, appropriate informed consent, etc.)

CIOMS 2017



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Social value

- Social value refers to the importance of the information that can vary depending on the significance of the health need, the novelty and expected merits of the approach, the merits of alternative means of addressing the problem, and other considerations
- Three factors that influence social value:

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- the quality of the information to be produced,
- its relevance to significant health problems,
- and its contribution to the creation or evaluation of interventions, policies, or practices that promote individual or public health
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Post research access

- Post-trial availability for communities and populations.
- Post-trial access plans are of particular concern for research conducted in low-resource settings where governments lack the means or infrastructure to make such products widely available.
- **Dissemination of results of research -** essential to achieving social value.



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Issues related to research design

Researches in the social and behavioral sciences make use of:

- 1. Quantitative designs (surveys, experiments)
- 2. Qualitative designs (grounded theory, phenomenological, ethnographic)
- 3. Mixed designs (either combination of quantitative and qualitative methods, or combination of methods within each qualitative or quantitative design).



Scientific soundness: Protocol sections



Methodology/ Ethical considerations

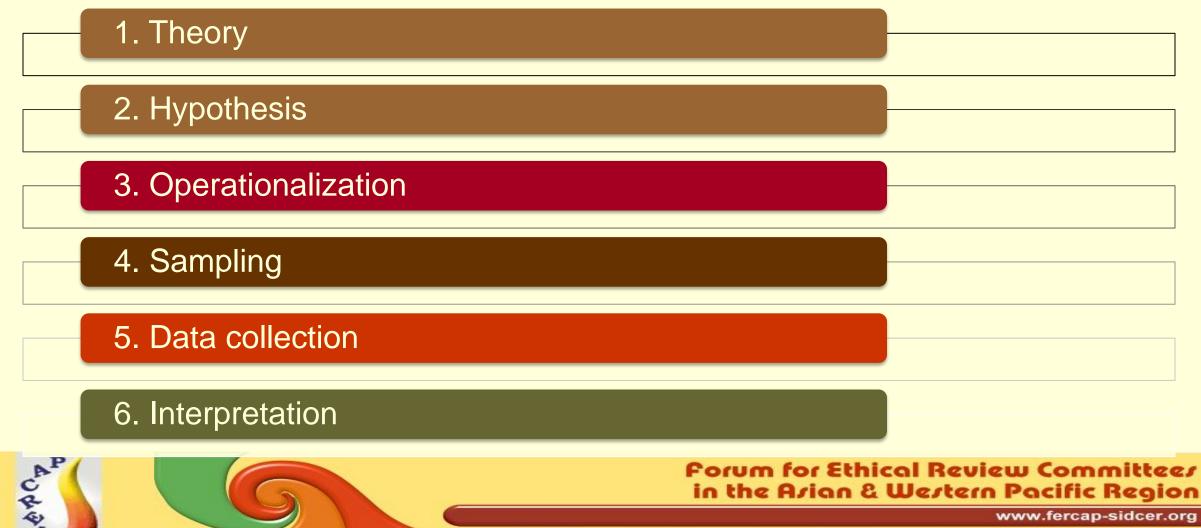
Data analysis

Outcomes



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Linear Model in Quantitative Research



Malaria prevention and control in Bhutan: Successes and challenges March 2011 • Acta tropica 117(3):225-8 DOI: 10.1016/j.actatropica.2010.11.008 Source • PubMed

Tashi Tobgay • Cristina Torres • Kesara Na-bangchang

Community directed intervention for malaria prevention in Bhutan: Quasi experimental study in malaria endemic areas in Sarpang district April 2013, Malaria Journal (12)1: 132. DOI: 10.1186/1475-2875-12-132 Source: <u>PubMed</u> Tashi Tobgay · Cristina Torres · Kesara Na-bangchang et al



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Quantitative Research

- □Aims to generate generalizable information/ conclusions
- Uses statistical methods
- Checks validity and reliability of data
- □States the data analysis plan
- Uses simple/ stratified random sampling methods in surveys



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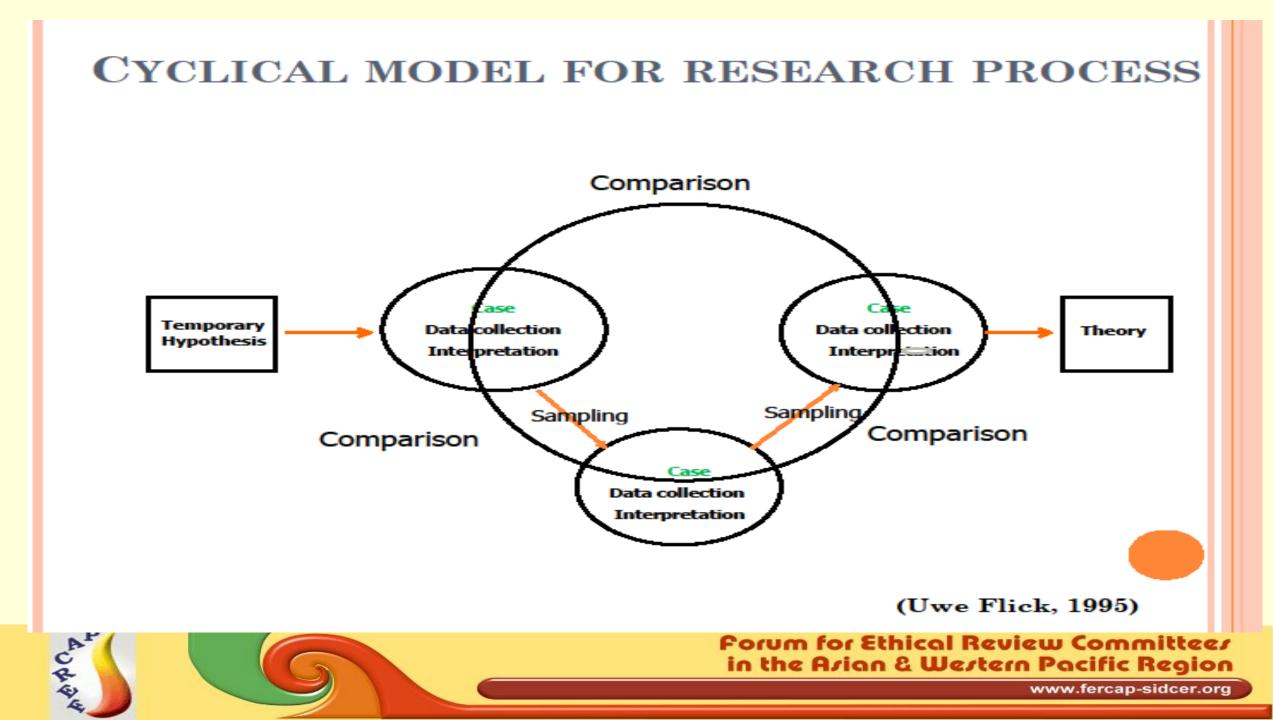
Quantitative Research

Quantitative – makes use of quantitative data for precise measurement of social phenomena.

- General patterns are described.
- Statistics are used to make statements of relationships of variables across many cases.
- Statistical tools include percentage, frequency distribution, measures of central tendency (arithmetic mean, median, mode and standard deviation)



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Qualitative Research Emphasize particular context and settings

- Use methods (ethnography, KII, etc.) capable of providing sufficient detailed account or analysis
- Outcome is capable of enabling others to determine the application of the findings to other circumstances

Provides in-depth insights about specific situations

Based on Australian National Statement on Ethical Conduct in Human Research (Sec.3.1.4 -3.1.8)

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Qualitative Research

Capable of generating quality and credible data based on its data collection techniques and analysis plan
No intention to generalize
Its rigor cannot be judged based on sample size

Based on Australian National Statement on Ethical Conduct in Human Research (Sec.3.1.4 -3.1.8)



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Grounded Theory

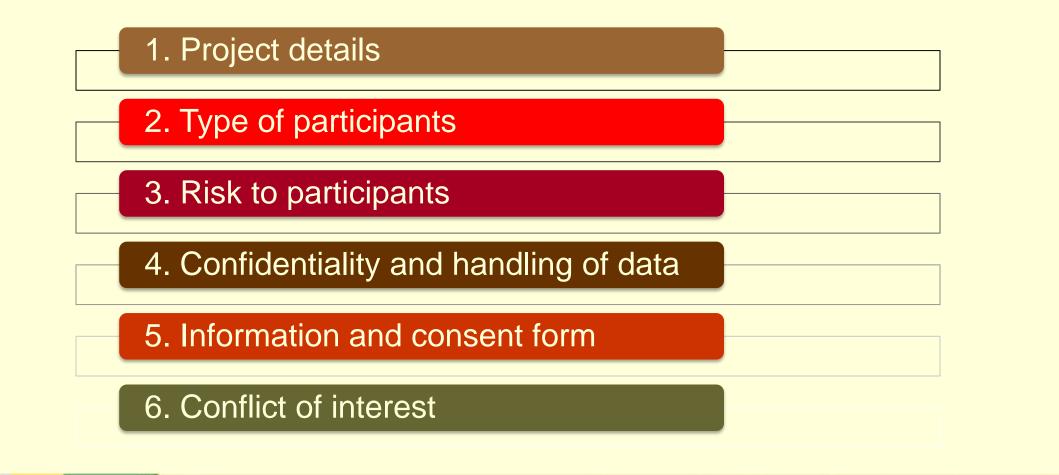
- A systematic <u>qualitative</u> research methodology in the <u>social</u> <u>sciences</u> emphasizing generation of theory from data in the process of conducting research.
- This contradicts the traditional model of research, where the researcher chooses a theoretical framework, and only then applies this model to the studied phenomenon.



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Ethical Considerations

University of Edinburgh School of Social and Political Studies





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Ethics in community research: Subject selection

- Burdens of research should not fall disproportionately
 - on socio-economically disadvantaged groups
 - institutionalized groups
 - administratively convenient. groups
- Poor people may be selected as subjects in research designed to address problems that are prevalent in their group (Ex. malnutrition or poor living conditions).



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Ethical Issues: Research about aboriginal groups

Australian National Statement

- Relevance of topic to community concerns
- Research methods should be respectful of the local cultures.
- Evidence of support from relevant cultural communities.
- Identify potential negative consequences of the research.
- Agreement with local groups about appropriate recruitment techniques, suitable information about the research and appropriate reporting of results.



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Ethical Issues: Overuse of certain groups

- Certain groups or communities within a society may be inappropriately overused as research subjects.
- Likely to occur in countries or communities with insufficiently developed human protection system
- Questionable when the populations or communities concerned bear the burdens of participation in research but unlikely to enjoy the benefits of new knowledge and products developed as a result of the research.



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Ethical Issues: Cluster randomized trials design

- Intervention is targeted to a whole group of people (Ex. students in a school or all residents of a community)
- Random assignment to the different arms of the trial. (Example: vaccination campaign applied at the school level)
- Individual persons usually do not have an opportunity to consent to the study itself but should be made aware of the study



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Ethical Issues: Cluster randomized trials design

- Individuals may not be able to decline participation in the study.
- Investigators have a responsibility to describe in the protocol the information that will be provided to the decision-makers and to individuals within the clusters.



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Ethical Issues: Cultural diversity

- Respect local customs by obtaining permission from a community leader, a council of elders, or another designated authority
- Use local language
- Develop culturally appropriate ways to communicate information
- Describe and justify in the research protocol the procedure they plan to use in communicating information to subjects.



Types of community consultation

Those consulted should be in a position to speak on behalf of the community or to reflect its views

- Review process by community representatives, particularly when the research originates outside the community or country
- Dialogue with the community about the proposed study and its potential implications,
- Conduct a more structured consultation that would document the concerns of a socially identifiable group
- In some cases, formal approval may be legally required;



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Planning for community consultation

- Researchers should have adequate time and resources to discern how the study population is organized socially and politically and which groups can best speak with authority for the population.
- Ensure that those consulted include all relevant groups and do not exclude women or minority groups.
- Plans for community review should be specified in the protocol, to allow their evaluation by the ethical review committee



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Consultation in a cluster randomized trial

- Identify an appropriate person or body (e.g., a community leader, headmaster, or local health council) that has authority to give permission for the cluster to participate in the study
- Scope of authority of decision maker should include interventions or the type of questions contained in the research project.



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Consultation in a cluster randomized trial

- Investigator should explain random assignment to one arm or another
- Decision-maker should ensure that
 - risks of participation in the study are commensurate with the benefits for the cluster or for society
- The decision-maker may choose to consult with a wider group of community representatives or advisers before taking the decision to permit the study.



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Ethical Issues: Research in communities with limited resources

Sponsor and the investigator must ensure that:

- the research is responsive to the health needs and the priorities of the population or community in which it is to be carried out;
- any intervention or product developed, or knowledge generated, will be made reasonably available for the benefit of that population or community.



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Competent Review of SBR

- SBR Panel membership
 - Scientific/ non scientific members (not medical/ non medical)
 - Technical primary reviewer with social science research experience to differentiate use of qualitative, quantitative or mixed method methodology
 - Non scientific member with community, NGO, social work, etc, experience



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Algorithm of Risk Determination

Assessment points

- Topic: Sensitive?
- Intervention: Risky? •
- Population involved: Vulnerable? •
- Level of risk •

No • Yes • Yes No No • Yes

Medium High Low •



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Competencies in social science research

- Scientific competence to prepare protocols
 - appropriate design (quantitative vs. qualitative)
 - Statistical tools for quantitative research
 - Content analysis for qualitative research
 - Community research skills (surveys, FDGs, KII, ethnography, etc.)





- Ethical soundness
 - Subject selection, recruitment and retention
 - Vulnerability assessment
 - Risk-benefit assessment
 - Confidentiality protection
 - Conflict of interest determination
 - Community consultation
 - Informed consent issues

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