

Participants understanding of their roles & responsibilities in clinical research in Blantyre and Chikwawa districts in Southern Malawi: expectation vs reality in practice

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Background

- Rarely discussed in literature are the responsibilities of research participants.
- Volunteers' understanding of their role appeared to lead to different interpretations of their trial task.
- Participants who understand and know what is expected of them in a study may more likely be more assertive and protective of their rights and those of others.

Aim of study

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To explore what participants and researchers understand as roles and responsibilities of participants in research .

Specific objectives

- To describe research participants' knowledge and understanding of their responsibilities and to describe factors enabling understanding of responsibilities.
- To assess the implications of the knowledge on research practice and to identify any similarities or differing views between groups participating.

Methods

- Cross-sectional qualitative study
- Purposive sampling
- Analysis: Thematic content analysis & framework

IDI	FGD	RESEARCH STAFF
Healthy CT n5	CT n8	Field workers n4
Sick CT n5		Research Nurses n3
Non- CT n5	Non-CT n8	Principal Investigators n3

Results

Research participation
as an opportunity for
help

- Medical services
- Financial/material incentives

Participants assumed
relational
responsibilities

- Helping researchers
- Influencing peers
- Dispelling myths

Researchers' functional
responsibilities of
participants

- Punctuality
- Commitment
- Understanding

Results

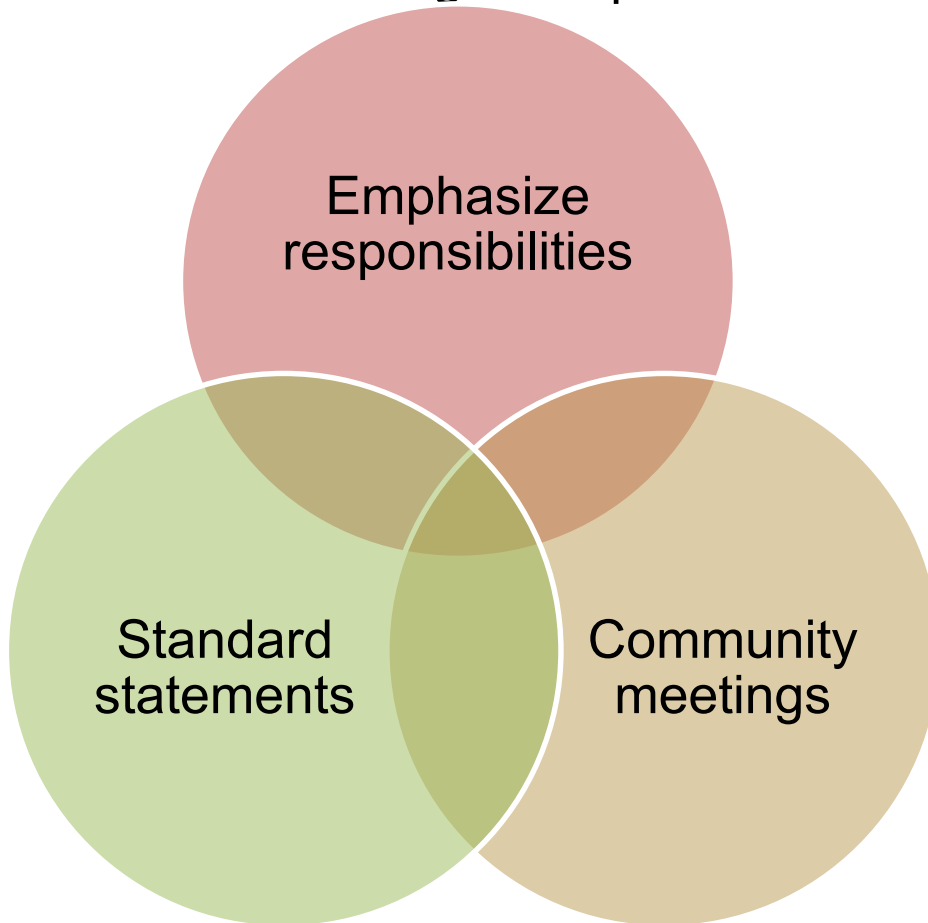
Apparent Disconnect in understanding of responsibilities

'the role that a person who is participating can have would depend on the information which you have given to them about the research. Let us say for example if s/he needs to have dates on which he can come to the clinic or you can meet him for follow up, then you have to explain to the person.' [FW 03]

'My role is to encourage people who have views like 'I cannot take part in research because research studies have these problems.' My role is to explain to those people the benefits of a research study.' [Male participant IDI 009]

Results

Suggestions to enhance understanding of responsibilities



“They should focus on the roles of participants in research because they dwell so much on things that will happen in the research. Like in our research they were dwelling so much on what will happen on the visit day.”[Male participant IDI 003]

Conclusions

- Motivation to participate in research by sick and healthy volunteers raise ethical concerns of the possibility of being vulnerable to undue inducement.
- The difference in perceptions of participants responsibilities between researchers/ front line workers and participants needs aligning through engaging research staff.
- Researchers should focus on how best to communicate responsibilities to enhance awareness and achieve mutual understanding.

Processes and challenges

Process

- Ethics application.
- Meetings with prospective host studies
- Potential participant given 7 days to read PIL and consult significant others if necessary
- Coding and content analysis
- Themes re-read and reflected
- Reflexive memos on themes of interest

Challenges

- Information sharing with host studies.
- Working within other people's projects.
- Getting Researchers as research participants

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