

Community Participation in a Research Study

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“Community Participation is not inherent, it has to be developed”¹

Introduction

Advancement in medical science depends heavily on bio – medical research. Though a lot of research is going on in hospitals and clinical laboratories, for a result to be termed successful, it should be applicable to the general population and policies need to be framed based on that.

The success of any community based research project depends on the design, methodology, treatment regimen, and other logistics involved. Since community based studies are resource intensive, and given that most developing countries are strapped for resources, effective management is particularly important in ensuring that resources are conserved. Another contributing factor is community involvement, without which even a well-planned study loses its validity.

From the researcher’s point of view, if the research question is to be answered with more valid data, he/she needs to have a high follow-up rate, which can be obtained only through the cooperation and participation of the community. To enhance the participation, high follow up rate and compliance, community involvement and support has to be sought from the inception of the study.

Community participation is promoted as an important component in the design of community health projects, improving content and process in several ways. Participation of community members in intervention development, increases the likelihood that the intervention is culturally appropriate in its format and content and will better fit the cultural systems of the community. For better participation, the role of the community and the benefits offered to them should be clearly spelt out.

This article provides a brief outline that may be adopted to gain community acceptance and participation in a community intervention trial.

Whom to involve

Community refers not only the subjects involved in the research but also various relevant groups of people, including administrative authorities who directly or indirectly have the power to influence and support the research. The research group should also give due regard to the structure, and cultural aspects of the community to be studied by involving religious and other relevant groups, without whose cooperation it may be difficult to proceed with the project.

Regional / District level

After getting the necessary approval from the Council of Medical Research and Ethics Committee, the regional/district level health authorities should be approached for their cooperation and support. The investigator should discuss the objectives of the study, the methodology, the risks and benefits of the research to the people involved and other additional services provided. The meeting with this group also helps both the parties to clarify their roles to prevent any adverse effects and avoid duplication of work.

Eg: A three year double blind community based large clinical trial on Vitamin A supplementation in Newborn (VASIN) children was conducted. It tested the efficacy of Vitamin A in reducing infant mortality rates. The newborns were given 50,000 I.U of Vitamin A within 24 hours of birth. To avoid over dosage of the vitamin, the local health care providers were asked not to administer Vitamin A within the study jurisdiction with the direction of the district health authority.

Community leaders

The initial contact in a community is likely to be with the formal and informal leaders such as village heads, panchayat presidents, and priests who can influence

the potential participants. The village heads and priests, even now, have a say in the village matters, sometimes even more than the elected panchayat leaders. If the research involves women and children, it is always advisable to contact the women's group such as the magalir mandrams (women's groups), traditional healers, self-help groups, dais (traditional midwives), and nutritional service providers in the community for better understanding and participation. A good rapport with the community can be established only if the investigator observes the local customs and acts accordingly. It is important that a person of sound knowledge and appropriate age approach the concerned group. The objective of meeting with the community leaders is to get their explicit approval of the study. The need for the study, objective, procedure, and the benefits to the subjects should be explained to the leaders in a simple and comprehensive manner.

Approval from the village leaders ensures better participation from the potential participants and others from the village.

Health care providers

The investigator should probe into the details of various health care providers in the village before starting the study. The objectives and methodology of the study has to be explained to the health care providers, such that services do not overlap. The discussions should also focus on the possible problems that will arise in the project, and the means to minimise such problems. Clear guidelines of their expected role in the project should be provided.

Informal health care providers within the community should also be considered. Local healers



Subjects participating in one of the community outreach programme

and traditional birth attendants often have a considerable influence in the community. Involving them not only helps the study, but will also leave behind an improved health care facilitator for the community.

Potential participants

The potential participants are the study subjects on whom the intervention is to be carried out. The success of dealing with this group is heavily dependent on the support provided by the community leaders. We can expect a better participation only if we are able to clarify the doubts and make them understand the objectives and benefits and get their explicit approval for the study. It is always better to have a series of meetings with the potential participants, if needed, to clarify their doubts. If the study is planned for a longer duration, intermittent community meetings inculcate trust and confidence in the study and will enhance participation.

Eg: In the Antioxidants in Prevention of Cataracts (APC) study, which has a 5-year follow-up, maintaining contact with the subjects for yearly follow-up is important to evaluate the treatment effect. Community meetings were organised at regular intervals (once in a year) to create awareness about the importance of participation and involvement throughout the course of the study. This helped to retain the interest of the participants in the study.

Ways to enhance community participation

1. Selection of field workers from the study area

It is beneficial to select the field worker from the area under study, as they are familiar with the practices and beliefs of the community as well as the area, which minimizes conflict between worker and the community. Furthermore, the workers are more motivated and committed, as it provides not only employment but an opportunity to serve the community they belong. It also encourages the community to share information without any resistance.

2. Prompt service delivery

In a community based research, it is always advisable to explain the potential risks and benefits of the intervention, to the subjects before the

commencement of the study. The staff has to be equipped to manage any adverse effects promptly. As subjects are randomised, ethically, the study should provide other necessary clinical services to them.

Eg: In the APC study, all the subjects enrolled are given eye care services at the base hospitals which includes minor surgeries, medicines and spectacles free of cost.

3. Scheduling data collection according to the community's convenience

Data collection should not interfere with the subject's routine schedule. Regular house visits for data collection has to be scheduled based on the availability of the people. In case of intermittent or yearly follow-up, the date, venue, and timing have to be fixed in consultation with the members of the community.

Eg: In the APC study, the subjects are evaluated on an annual basis for evaluating the effect of antioxidants in lens changes. The procedure involves a comprehensive eye checkup and takes an hour. Each year the date and time for this evaluation is finalised by consulting the subjects involved. As a result, 98% of the subjects were followed up consistently for the past three years.

4. Incentives

One may think of compensating individuals, in the form of money or food for time lost from other activities which may be work related. These compensations must be carefully studied from an ethical standpoint, and they are generally discouraged. However, for each situation, it is advisable to review the merits and demerits in the local context.

5. Feedback of research results back to the community

At the completion of the research, it is the responsibility of the study group to inform the community, of the results, in a manner that the community members can understand the implication of the findings. It is always better to inform the progress of the results to the community intermittently, which definitely will enhance the participation throughout the study. Also, at the end of the study, the results should be shared with the health agencies for policy making and implementation.

Framework for conducting a community meeting

Content of the Meeting

In the meetings with the community leaders and potential participants, the information about the trial should be presented in such a way that it could be understood by all. The investigator or the person who is giving the talk should take in to account the culture and belief of the people in the village. He/she should be careful in talking about sensitive issues – especially issues related to women and other issues considered as taboo from the local cultural context.

The participants should be informed of why the study is undertaken, the outcome of the study, procedures involved, the possible benefits and risks involved, why the particular population is selected (Inclusion criteria), and the need for informed consent from the participants. Individuals as well as the community leaders must be told that participation in the study is voluntary and those who refuse will not be discriminated in any way.

Further, they should also be explained the reasons why particular tests (e.g., blood test) are done and the need for such tests. The subjects should be assured that all the results would be kept confidential. As a researcher, the investigator has a moral responsibility to provide free services for adverse effects. The investigator should take this opportunity to introduce the local volunteers identified in the village for carrying out the study.

Method of presentation

In any community-based research, the manner in which information is conveyed is crucial for better participation by the community members through



Presentation during a research study

enhanced understanding by them regarding the project details. Visual presentation of the research study helps to convey the message quickly and enhances the retention ability. Audio – visual aids and other visual presentations like video show, skit, and dramas can be tailored to express certain aspects of the study.

It is always advisable to fix the venue and time of the meeting in consultation with the village people. The time for the meetings should be fixed based on the availability of the subjects.

Eg: In the APC study, usually the meetings will be held in the evenings (5.00pm) wherein all of them will be available.

Duration: Another important aspect to be considered is the duration of the meeting. A meeting can be planned for 45 to 60 min so that the audience do not feel restless.

Venue: Venue of the meeting is another important aspect that has to be taken in to account. The venue chosen should be a common place in the village, like a school or a community hall that is easily accessible to all. Meetings should not be arranged in people's houses or in religious places. It may lead to problems with certain people refusing to attend the meeting.

In trials that involve large sample size, the investigator should have an idea of how many people

to involve in a meeting. A manageable number can be chosen and a series of meetings can be held for conveying the information and to ensure effective participation. In many villages people often expect some refreshments in a meeting. The investigator should make provisions for it in the study budget.

Conclusion

A well planned research design and methodology ensures that the study is being carried out properly. Active involvement and support from the community helps in obtaining valid results from the study and to maintain the integrity of the research. It is also a major contributing factor to tackle any challenges or crisis that could be encountered during the course of the study.

Points to remember

- Selection of workers from the study area
- Gaining their trust and confidence through community meetings
- Prompt service delivery
- Sharing of results back to the community
- Culturally appropriate incentives
- Commitment from field staff
- Scheduling according to the community's convenience

Reference

1. Peter G.Smith and Richard H.Morrow, *Field Trials of Health Interventions in Developing Countries*