

## Case Report

# Pursuing Primary Health Care: Community Participation in Practice, Doing Participatory Research

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## Abstract

Of the two key principles of Primary Health Care, equity and community participation, the later has been most difficult to implement. Early attempts focused on creating Community Health Workers (CHW) and mobilizing communities to take up health interventions defined by health professionals. Both approaches had considerable difficulties with being cost effective and sustainable. As a result, interest in community participation moved from health promotion to empowerment. Empowerment focuses on providing opportunities for community people to gain skills and experiences to take an active part in decisions that affect their own lives. Participatory research is one main area that enables training and experience for both professionals and community people to support empowerment goals. The purpose of this paper is to review how participatory research can contribute to improved health outcomes by involving community people in the design, implementation and evaluation of a health intervention. To do this the paper will examine the definitions of participation, a history of the development of the concept of participation and its contribution to improved social welfare and health, principles for participatory research, and some of the emerging strategies, using examples, including the contribution of qualitative methods to support these strategies. The final section will address issues concerning the future of participatory research.

## INTRODUCTION

The Alma Ata declaration signed by member states of the World Health Organization (WHO) [1] in 1978 articulated a policy entitled Primary Health Care (PHC). It was based on the principles of equity and community participation. While equity commanded fairly immediate attention for improving access to health services for especially the poor, implementing community participation was more challenging. Early efforts focused on creating cadres of community health workers (CHW). However nation programs faltered concerning decisions about how the government would treat CHWS. [2] Would they be incorporated as part of the government's civil service? Would they be paid or non-paid volunteers? Who would pay them?

Only 10 years after Alma Ata did WHO publish a book on community participation [3]. However in recent years community participation has gain prominence in both programs and policy. With growing concerns about sustainability of interventions to improve health of populations and of cost-effective ways to ensure sustainability, community participation has captured attention of health policy makers, managers and those involved in health service delivery. The reasons include:

1. Being involved in decisions about health services, people are more likely to respond positively to the value of these services.
2. Improving health of the community is likely to be more effective when people contribute collective energy and resources (time, money, materials and energy).
3. Risky behaviors can be changed when people are involved in deciding about that change.
4. By gaining information, skills and experience in community health projects, people have the potential to take control over their own lives and challenge systems that have sustained peoples' deprivations [ 4].

Community participation has most often been identified as CHWs or social mobilization [5] by which professionals design a health intervention and by providing information try to convince community members to accept change in behaviors to support the intervention. However increasing evidence shows that in order to have interventions effective and sustainable communities need more than information (health promotion). They need to be involved in decisions about the implementation of the interventions (empowerment) [6]. The purpose of this paper is

to review how participatory research can contribute to improved health outcomes by involving community people in the design, implementation and evaluation of a health intervention. To do this the first section will examine the definitions of participation. In the next section, a history of the development of the concept of participation and its contribution to improved social welfare and health will be briefly discussed. The third section will seek to define some principles for participatory research. The following section will focus on some of the emerging strategies, using examples, and include the contribution of qualitative methods to support these strategies. The final section will address issues concerning the future of participatory research. It will suggest that experience illustrates that it is more useful to see participation as a process that supports an intervention than as an intervention in itself.

### WHAT IS PARTICIPATION?

A classic definition was provided by Arnstein (1969) who described participation as a “ladder” with the lowest rung as manipulation and the highest as citizen control [7]. The concept of participation in the area of health care has generally come to mean the involvement of intended beneficiaries in improving health care. However, there is no standard acceptance of what exactly participation means. It has been defined as activities undertaken by health professionals to sensitize people about the need to be involved in health activities and undertake local initiatives. It has been defined as having local people involved in decisions about programs. It has been defined as organized efforts to have intended beneficiaries manage and control health programs and activities [8]. Given the wide diversity of definitions that range from professionals telling people how to act to having people take full responsibility for their decisions, it may be best to view participation on a continuum. At one end there is participation as information sharing; at the other there is empowerment [9]. How participation is defined depends on the objectives of planners who want to have participation in health programs (Figure 1).

For planners to decide at which point of the continuum, their participation objectives are to be placed, the following questions might serve as useful guides.

1. Who defines “the community”—intended beneficiaries or professionals?
2. Is participation a means by which to pursue program objectives (such as health improvements) or an end in itself (such empowerment) [10]?
3. Who defines priorities and actions? In other words, where is the power over and control of the intervention and/or accompanying program [11]?

### A BRIEF HISTORY THE PARTICIPATORY APPROACH FOR HEALTH IMPROVEMENTS

To understand why participation as a planning approach increasingly influences health research it is useful to briefly review the history of its development. Two theoretical constructs can be identified that trace the changing view of participatory approaches from social mobilization to empowerment and



**Figure 1** Information sharing Consultation Collaboration Full Responsibility.

correspond with the political and economic environment of the time [12]. Participation came on to the health agenda in the Post World War II period. It was seen as a way of addressing problems of poverty among the majority of the world’s populations. Its early focus was on improving living and health situations for the poor in both the urban areas of the industrial world and the so-called developing countries struggling with poverty, lack of resources and decolonization. During this period the theoretical construct of “community development” was predominant. This construct assumed that communities were homogenous and were able to agree upon health actions when professionals educated and supported their efforts. [13,14] This support would lead to self-reliance and mobilization of local resources (materials, money, human resources) that would result in an improved and sustainable health environment.

By the 1960s, however, it was clear that the answers to poverty and health improvements could not be found in merely mobilizing communities. The assumption those communities were homogeneous—wanting the same things at the same time proved to be false. Problems of poverty, it was pointed out, were problems on inequities caused by the screwed social structures. The United Nations, under the term of “peoples’ participation”, put forward arguments and action to address issues around power and control of resources [14]. These focused on changing social, economic and political structures in order that the minority that commanded resources would share the decisions about allocations with majority who were to be seen as subjects rather than objects of development. In directly addressing power relationships, this construct advocated revolutionary political change.

During the 1980s, the global economic crisis and the increasing global information system began to moderate aspirations of the “peoples’ participation” approach. The interlinkages among nations and people focused the interests in participation on capacity building of local people to manage their own lives rather than attacking the structures that kept them impoverished. [15] Participatory approaches shifted the emphasis from revolution to empowerment. Robert Chambers [16], a major advocate of this construct, argued that a whole new paradigm for action and research was necessary. This paradigm was one that: 1) recognized the ability of the non or poorly educated people to make and carried out rational and successful decisions and action formerly the responsibility of experts; 2) allowed innovation to be spread by peer groups not only professionals 3) brought about a role reversal where local people became colleagues of professionals thus generating a change in the professionals’ attitudes and behaviors. Following the economic and social

developments of the times, participation began to focus on the individual rather than the community as a whole.

## FOR PARTICIPATORY RESEARCH

While the constructs described above appear to focus on action outcomes, a major spin off of the intellectual development was the inception of participatory research. Participatory research is often used interchangeably with the term “participatory action research”. Many attribute its inception to the work of Kurt Lewin, a German sociologist, who in the 1940s investigated decision-making in an American factory. His findings gave evidence that a greater level of worker production and satisfaction was to be found when workers participated in decision making rather than taking orders from above [17].

The development of this type of research became known as action research. Hart and Bond have defined action research in the field of health [18].

- They describe action research as that which:
  - Is educative
  - Works with individuals as members of social groups
  - Sees research as problem-focused, context-specific and future-oriented
  - Has a change intervention (has a specific intervention to seek an identified change)
  - Strives for improvement and involvement
  - Undertakes a cyclical process whereby research, implementation and evaluation are interlinked
  - Has as the basis a research relationship in which those involved are participants in the change process.

These characteristics form the principles of Action Research. However, the principles of participatory action research require some additions.

Participatory Action Research (PAR) expands the later principle to ensure the issue of empowerment of the intended beneficiaries is addressed. Building on the work of Paolo Freire [19] and later, Fals-Borda [20] and Tandon [21] PAR seeks to ensure that all those concerned with the research outcomes, professionals and intended beneficiaries, are involved in the entire research process from inception to implementation. PAR must enable all participants, professionals and lay people, to learn and expand their capacities. In the case of the poor and uneducated, it must be recognized also as a political process whereby they will be able to liberate themselves and use their potential to solve their own problems [22]. This principle demands that other principles reflect the ultimate goal of capacity building and empowerment of intended beneficiaries. It also, consequently, demands a change in the attitudes and behaviors of professionals to accommodate this goal, a view that is the foundation of the empowerment construct.

## STRATEGIES FOR PARTICIPATORY RESEARCH

Participatory research, by definition, is people focused. It has the dual objectives of improving information and data by involving those concerned with the outcomes and enhancing the

capacity of the intended beneficiaries to decide upon and manage the outcomes. For this reason, participatory research relies on qualitative methods. These methods allow researchers to begin to see how intended beneficiaries view the world and to form a basis by which beneficiaries have an active part in transforming that world, in this case, for better health. To be more explicit, qualitative methods enable researchers to: examine a process to see how ideas and actions have changed over time and why these changes have taken place; to see how people view their world and why they use different ways of dealing with that world; allow the researcher to work closely with those who are to benefit from suggested changes; gain hands on experience from field work; and involve the intended beneficiaries in the research process [23].

While the traditional qualitative methods (interviews, observations and documents) provide the basis for research, a combination of the first two with a more innovative method, visualizations, has marked the development of this type of research. Visualizations have made a major contribution because it has allowed those who are not professionally trained, and often not even literate, to become integrated into the research process. Visualization depends on visual presentations of data. Most popular are drawings by beneficiaries of their own living situations that allow researcher (s) and local people to dialogue about the problems and potentials of that situation. This use of visualizations has become known in the literatures as PRA (Participatory Rural/Rapid Appraisal) and more recently as PLA (Participatory Learning and Action) reflecting the idea that participatory approaches are neither only rural nor not rapid [24].

In promoting participation, visualizations are noted to have the following advantages. They allow non-professionals to give their own ideas without having professional’s record and/interpret the information for them. They allow those who are to benefit from the intervention to express their knowledge and feelings about the situation. They generate a great deal of information in a short period of time and it can be understood by those outside the research process. They provide opportunities for all those in the research process to gain new understanding and insight [9]. In terms of empowerment, they are seen to release the monopoly that professionals have held on the research process.

Examples of visualizations include asking beneficiaries to map their local communities, to use matrices to rank priority problems and solutions, to draw historical time trends and with children to ask them to draw their experiences in a technique known as draw and write. This paper is too short to give examples of these methods but a detailed description of how, where and when they can be used can be found in *Partners in Planning: information, participation and empowerment* [9].

Strategies for PAR in the health field based on qualitative methods including visualizations have been best developed in the areas of needs assessments and to a lesser degree in the evaluation of health programs. A good example is that of using Rapid Appraisals (RA). Rapid Appraisals were developed and used in both the developed and low and middle-income countries. Beginning in the 1980s, they were applied in both the areas of health and development. Using the term “Rapid Rural

Appraisal" (RRA), an approach was created to obtain information about the situation of the poor that did not rely on the traditional quantitative survey method. The approach was attractive to those in the health field not only because of the speed in which information could be collected but also it supported two major planks of Primary Health Care, those of community participation and intersectorial collaboration. RRA was characterized by data collection undertaken by a variety of professionals from different sectors that included health, by involving potential beneficiaries in the data collection process and using an iterative approach to improve the planning process [25].

## ISSUES FOR CONDUCTING PARTICIPATORY RESEARCH

Participatory research, as we have said, is research that brings the intended beneficiaries, into key roles of the research itself. In many cases these beneficiaries are lay people with little training in any profession and not exceptionally, are illiterate. The interaction between professionals and the beneficiaries raises a number of issues.

Firstly, and key to the research, is the issue of training.

- Who and how?
- What is the future for the trainees?
- How can the attitudes and behaviors of professional researchers be addressed?
- Secondly is the issue of the time and cost of undertaking such research.
  - It takes a long time to identify research question if non professionals are involved. If professionals take over it reduces participation.
  - The cost of the research is unpredictable and could be high. This is not a great incentive for funders.
- Thirdly, there is the issue about the power over and the control of the research and its findings.
- Who owns the research?
- Who publishes?
- Do professionals exploit the lay people?

## FUTURE OF PARTICIPATORY RESEARCH

The above discussion has focused on strategies and issues for carrying out participatory research. It is equally important to discuss the value of these strategies to health improvements. Perhaps, the most important use of this type of research has been its contribution to addressing poverty alleviation and the plight of the poor. It is argued that involving those who are without power, resources and influence in the needs assessment and consequential planning procedures will insure their influence and control over the outcomes [16]. While the argument has great emotional appeal, there has been evidence to question this premise. In a book entitled "Participation: the new tyranny?" authors show that many of the assumptions that underpin the contribution of participatory research need to be questioned [26]. Various contributors suggest that the views that: 1)

participation is the key to program sustainability 2) participation always leads to empowerment and not to manipulation 3) participation liberates the poor and ensure their empowerment are not substantiated in specific case studies. Although both practitioners and theorists have supported some of these views orally, the publication of this book places, what might be considered hearsay, into the public domain.

Another concern is that of evaluating the contribution of community participation to health improvements. Evaluation of health improvements uses the gold standard of Random Case Control Trials (RTC). However this approach has failed to identify the value of community participation in the context of being reliable, replicable and generalizable. A major reason is that there is no standard definition for either "community" or "participation". In using the RTC approach community participation has been identified as an intervention. Because of the nature of participation as described in this example of participatory research, it has been argued that community participation is better conceptualized as a process which changes over time and relies on context [27]. In recent years, evaluation frameworks taking this aspect into account are being developed [28]. The potential of these frameworks improve the understanding of participation and how it can support health improvements.

## CONCLUSION

Participatory research as the potential of enabling intended beneficiaries to learn skills and gain experience to improve their own lives. It also enables them to take ownership of a program to improve their health. It has been the basis of a program entitled Community Based Participatory Research (CBPR) popularized in the United States that builds on partnerships between universities and local communities to improve community health [29]. It also has been the basis of various Non Governmental Organizations (NGO) programs for health improvements in low and middle-income countries. As policy planners, managers and health service providers seek to find sustainable and cost-effective ways to improve health care especially for the poor participatory research provides potential answers to show a way forward.

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