

# The potentials of involving communities in health research



Article by Selemani S Mbuyita

*"... We live, after all, in a world of increasing polarization of power and wealth into North and South, into overclasses and underclasses. Materially, those in the overclasses have more and more, and are increasingly linked by instant communications. At the same time, the numbers in the underclasses of absolute poverty continue to rise. Among them, many millions have less and less, and remain isolated both from the overclasses and from each other. Almost by definition, the poor and powerless have no voice. It may be politically correct to say that they should be empowered and their voices heard. But cynical realists will point to inexorable trends, vested interests and pervasive self-interest among the powerful, and argue that little can be changed" (Robert Chambers, Whose Voice?).*

For anyone who has been in research and applied any of the many branches of participatory research methods, turning back to the conventional empiricist survey approaches or any other "quick and dirty" data collection techniques would be difficult. The facts revealed, the knowledge acquired and the skills unveiled from the people in communities where the research process is implemented, differentiate distinctly participatory research (that involves communities) from other research methodologies.

Literally, participation can be defined in different ways. However, in general terms the concept of participation reflects the action of taking part in an activity. People "participate" in local development every day through their family life, livelihood activities and community responsibilities. The degree of control that men and women have over these activities varies. The same holds true for initiatives that are initiated or involve "outsiders" such as *research projects*, development programmes or advocacy campaigns<sup>2</sup>.

The potential of participatory research comes from the researched people as active analysts of the researched subjects. With participatory research, solutions to research questions *come from the people supported with data, and not from data supported by trained data analysts*. Interventions and/or programmes developed using data from the first scenario are more reliable, feasible and sustainable in their implementation than the latter. Historically, health policies that have been designed without a community

participatory approach, some of which have acquired a global attention, often have failed to solve people's health problems. The trend will be the same and the vicious cycle maintained unless the participatory research community can succeed to show, demonstrate, convince and prove to local and global health policy-makers that participatory research has the potential to solve many of our health problems.

To address these concerns, special attention has been paid for the past few decades to the development and analysis of participatory research methods. One stream of participatory research, with new inventions, evolved as a family of approaches and methods known as Participatory Rural Appraisal (PRA). As PRA evolved, it soon became evident that it had applications for policy. Thematic and sectoral studies were carried out and resented as reports to decision-makers, sometimes within only days or weeks of the field work. The World Bank, through trust funds from bilateral donors, initiated Participatory Poverty Assessments (PPAs). Some of these used PRA methods to enable poor people to express their realities themselves. The insight from these thematic studies was striking, convincing and unexpected. However, it was (*and still is*) too scattered and/or fragmented for full mutual learning or for its significance to be fully seen<sup>3</sup>.

Health programmes that were later proposed and implemented worldwide, with elements of involving communities in their implementation had their roots in evidence revealed by participatory research. Today, we identify programmes and interventions such as School Health Programmes, Community Based Health Initiatives etc. that were designed to respond to unveiled potentials of beneficiaries' involvement in such programmes. For example, the concepts of the *Health-Promoting School* and of *Comprehensive School Health Education and Promotion*, as discussed and defined by WHO, have highly considered participation concepts<sup>1</sup>. Partly, this programme aims to counter the views adults and teachers commonly hold of children and young people as ignorant-to be taught;

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irresponsible-to be disciplined; immature-to be brought up; incapable-to be protected; a nuisance-to be seen and not heard; or a resource-to be made use of<sup>7</sup>. Participatory research, resulting in participatory data to generate participatory solutions through participatory interventions and/or programmes, were demonstrated to be successful in averting and/or changing such views.

Community involvement in health research and in other domains of development is a strong tool towards such change. It helps to teach those who hold such views and perceptions that they can learn a lot from children, poor people, and unschooled and illiterate men and women – that there is much to appreciate, so many skills to acquire and adopt. Learning such lessons is important if our research is to bring positive effects and make a difference. These realities are easily seen once one gets involved in the process of participatory research.

The following sets of questions and case studies will help to demonstrate the potential of applying community participation in health research, and will help bring everybody aboard – including those with practical experiences of participatory research in health and those without. Indeed, they might assist in changing even those *cynical realists who usually point to inexorable trends, vested interests and pervasive self-interest among the powerful, and who argue that little can be changed*.

### What does participatory health research look like?

Most of us have some understanding of what it *means* to use participatory approaches in health but *how* to make it happen may be less clear. There are some basic principles to using participatory methods:

1. Local people are creative and capable of undertaking their own investigations, analyses and planning.
2. Outsiders (*field workers, facilitators, researchers etc.*) have a role as facilitators of this process.
3. Local people can and should be empowered to solve their own problems themselves<sup>4</sup>.

This means that, when conducting health research using a participatory approach the method:

1. should not only extract information from people, but should also recognize local knowledge and make use of it;
2. should not end at collecting data but, should stimulate a process that would discuss issues identified from the data;
3. should not try to create solutions to the identified issues, but rather involve the people themselves to formulate ideas and initiatives to solve their own problems.

Due to its nature of involving people, methods applying community participation are usually intertwined; issues raised are of time taken, expectations aroused and whose realities are expressed.

As a result, participatory research is time-consuming. The methods used, especially the visual ones like mapping, diagramming and matrices, tend to be fun and engage people's full attention.

Expectations are liable to be raised. After being helped to analyze their conditions, problems and opportunities, people often expect action<sup>3</sup>. Unfortunately, many research activities end at this point, instead of proceeding two steps further where planning for action and follow-up would actually be instituted.

Throughout the process of community participation in health research, transparency must be maintained. Outside researchers should make clear from the start who they are, what they are doing, and why, and what can and cannot be expected.

### Can every health research question be answered using participatory research?

The classical classification of research is usually very wide. Some research questions traditionally have been associated only with specific research design and methods. For example, a malaria vaccine trial typically would be seen to appropriately require a clinical trial design. However, it is possible to argue that, participatory methods are also

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important to answer questions in clinical trials. For example, in preparing for a malaria vaccine trial in Bagamoyo, Tanzania, a component applying participatory research methods was included for introducing the study objectives and creating awareness within the community in the study area. It also helped to extract information about people's expectations, worries and fears and increase the readiness of the research project to address individual and community concerns before the vaccine was introduced. The participatory research component also helped to solicit people's views (from the people who would later be the active participants of the process) on how best to make the project, and ultimately the vaccine intervention, a success.

The experience of this participatory approach to the malaria trials was that some of the issues raised by involving the community at that early stage of the project had not been well thought out nor understood in advance – *and actually could not have been known by "professionals"*. Had the trials proceeded without this process, the existing "knowledge" would definitely have misled the trial.

This example, and others that can be cited, support the argument that participatory research in health can be applied to a wide range of research questions, including those that usually seem to be too scientific to involve local people. However, the nature of the participation of various partners in the research process (local people, key community persons, community leaders, political leaders etc.) varies with the nature of the study, research design and scope of work involved in the research process.

Generally, any research question can apply and employ participatory approaches. In the Tanzania Essential Health Interventions Project (TEHIP), the Community Voice Component employed Participatory Action Research (PAR) in trying to answer the question, “How can communities be effectively involved in district health planning processes?”. The initial objective was to develop a procedural framework for incorporating Community’s Voice into District Health Plans<sup>5</sup>. Traditionally, stern professionals with a sound background in participatory methods and community involvement would have been contracted to develop such a framework. However, by using a participatory action research approach, communities in selected study districts significantly contributed to the design of such a framework (planning tool). The result was the availability of a practical tool that took into account the views of both professionals and the community.

### What can participatory health research achieve?

Like in any other type of research model, the key product of community participation and involvement is data. Data generated through a participatory process normally produces richer information than that from a classical data set. The form in which the data is normally made available is clearer and easier to be understood by all those involved in the research process – as well as by those who were not – than are classical data sets from surveys.

Apart from the data, an additional value of a participatory health research process is the interaction that happens between the *outsiders* and the communities. This interaction is very important for understanding social factors, such as how people understand disease, that may influence people’s health-seeking behaviours and patterns of health care use<sup>4</sup>. In a later stage, this understanding is important in designing health services that reflect people’s culture and use local knowledge, which in turn has been shown to increase acceptability of the services, compared to services that do not take these into account. Even where health infrastructures are available, providing information in one’s own language, ensuring culturally appropriate care or supporting community networks for prevention and follow-up of illness, are all important factors in improving access to care. Research processes that have involved people as active participants have brought about these effects and impacts.

There are three main levels of impacts on the community, from which we can deduce what community involvement in health research can achieve. Each level has a different scope, but each is equally important:

1. The immediate impacts and direct benefits for individuals and families.
2. The broader impact on “social capital” or local organizations, namely the empowerment and representation of communities and their members.
3. The overall impact on local society.

At each level, the forms of expected impacts may also vary. Impacts may have material, human and spiritual attributes.

These are seen across a continuum of tangible and intangible impacts, including environmental, productive, and physical changes, as well as overall transformations at the individual and community level. Tangible impacts are changes that can be observed directly, and measured and documented quickly. Intangible impacts are more subtle, internal or attitudinal changes that can also be documented but often in a more “qualitative” manner<sup>6</sup>.

### Can participatory health research approaches achieve everything?

Participatory approaches that involve communities are basically reflective and are primarily qualitative in nature. People who are used to drawing conclusions using numbers and figures might be a bit disappointed, although even quantitative information can be gathered through participatory methods. Tools used in participatory research are designed to gather people’s knowledge generated from their own opinions and experiences. By definition, much of this knowledge is not measurable in the scientific sense of the word but, nevertheless, vital if communities and outsiders are to work successfully together in improving the health and well-being of individuals, communities and the nation.

At the same time, this does not mean participatory research and action ignores quantitative data i.e. data that is counted or measured. There are examples of participatory methods for research in health that provide evidence that is quantitative. We can use participatory methods in health research to produce averages and other quantitative information<sup>4</sup>.

### Who should be involved when community participation in health research is applied?

Beyond the immediate networks of households and families, there are *social groupings* within “communities”. These social groups share a common experience or situation. For example they share the same social class, income level, gender, geographical area, age, ethnic or religious group, political status or other social and economic factors or experiences. These factors and experiences can influence how healthy they are, how they are able to create and sustain their own health, how they are exposed to disease, and how much they are affected by ill health. It can also influence how well they are served by health or other community services that affect their health, or how they access those services. For example, disabled people as a social group face particular difficulties in achieving the conditions needed to create and sustain their health. They are often subject to stigma, discrimination, and social marginalization and exclusion that prevent them from participation in the lives of their families and communities, schools, workplaces and income-generating activities and from benefiting from the results of that participation. Often, their health needs are not recognized and they may experience exclusionary criteria from medical and other community services necessary to their health. In addition, access to health services is often made difficult or impossible because of architectural barriers, lack of accessible transport and inappropriately planned and designed health services.

Several strategies are needed for each of the identified social groups we have identified to build interest and become actively involved in health activities. One of the first of these is for people to be aware. **Information is power.** The community that is well informed about the existing health activities stands a better chance to raise their voice, debate and demand inclusion, participation and social justice. We thus need to include in the design of any programme, components that provide for awareness creation, for listening to inputs from communities and feeding information back to communities.

It is practically impossible to involve everybody throughout all stages of implementation of a health research, programme or activity. Different stages of the programme will involve different people in the community. For example, during the introduction, awareness creation and sensitization of the health activity, all community members would preferably be involved. However, at a stage such as planning, representation is important as it is not possible to have all the community members in a planning meeting. Representation is more easily achieved if we know the different groups that need to be represented and ensure that their interests are all addressed.

It is important when we talk of participatory research in health to look beyond community involvement. If for example our research is to influence the policy-making process, it is very essential to identify other partners of the process and involve them in earlier stages of the research process rather than waiting to involve them at results dissemination and programme design. This would include policy-makers, the media and other key stakeholders.

Policy development is complicated and involves a number of players with diverse interests. Policy interests at local level may differ from those at global level. Take for example medicines. At the community level, the interest is to make sure that when people fall ill, that they have medicines at the nearest health facility. At the district level, decision-makers may balance the priorities for drugs for treatment against spending on prevention, water supplies, improving antenatal services and so on. At national level there may be issues about how much foreign currency is spent on drugs versus fuel and other essential goods. At the global level, there may be trade rules to do with protecting patents for large companies that may limit the options of what countries can do<sup>4</sup>.

Therefore, for communities to effectively work with, engage or influence institutions at different levels it is necessary to understand how these institutions are organized, their roles, how information flows between them, and who their authorities are. If possible, a research process that intends to engage communities, should also consider other partners from the public departmental sectors, NGOs and Civil Societies with shared values and interests in the area being researched.

### In summary

Community involvement in health research is about facilitating change. If it is used as it should be used, it can

lead to major shifts in the way people and organizations think and act. When using participatory approaches, practitioners are encouraged to move away from the concept of “them” and “us” to recognizing that health “belongs to us all”. The attitude and behaviours of the practitioner is central – listen to people’s own knowledge, create dialogue, involve people and institutions at all levels in decisions and activities.

Everybody can learn and acquire “knowledge of” participatory methods but not everybody has the skills to implement them. Participatory skills are not “acquired by learning” but rather “by doing after having learned”. This makes community participation an area where skills grow through practice and through getting feedback from colleagues and communities.

Health research applying a community participation approach uses a diversity of methods that is limited only by our own imaginations, which are limitless. The methods are flexible and can be adapted to different circumstances. Participatory methods are very strong tools for generating qualitative data; however, some methods can also generate quantitative data. Participants with guidance from facilitators can do their analysis in the field, producing results quickly and discussing and moving ahead with actions. This is cost effective and results/reports are produced and shared in a timely fashion.

Involving communities in health research can be time consuming, but can often be done with local resources and may not be costly. They are not like “quick and dirty surveys”. They need significant listening skills. Some issues may call for several rounds of reflection, action and then analysis and reflection leading to further action.

Approaches that empower people and lead to change may be threatening to some groups or interests in communities, and change may be resisted. There may be opposition and resistance to participatory research for these reasons. Like any other method, participatory methods are also open to abuse, and can be used in the wrong way for the wrong reasons. Not every method can work everywhere<sup>4</sup>. □

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