Chapter 10: Participatory research

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1.   Introduction

Participatory methodology in health systems always involves members of a local community. However the term 'community' can be used in many different ways. It can applied to administrative or geographical units or social, even global, categories. People who suffer from a medical disorder are often seen as a community by those who do not share their condition, including doctors, but may not see themselves as a community. People with HIV, diabetes or another chronic disease may share little besides that disease. Different definitions and interpretations of the term community has led to diverse expectations, perceptions and experiences amongst different stakeholders, and confusion as to the findings from program implementation, evaluation and research (Mansuri and Rao 2003, Schmittdiel 2010).

The social, administrative and local boundaries of communities therefore need to be carefully defined at the outset of a health intervention and used consistently during research in order to avoid misunderstanding and facilitate measurement and interpretation. What a health system is – and by extension what it is not – also needs to be established. As discussed in chapter 1, for some it includes a variety of informal health sector actors including unqualified providers, religious healers, patient organizations, and mobile pharmacies on the back of a bicycle. Others limit it to state sanctioned formal actors. This chapter is not about discussing the merits of alternative definitions but it is important to specify these before embarking on participatory research, as they are essential in delineating the context and identifying stakeholders.

2.   What is Participatory Research?

In this section we discuss some of features that distinguish participatory research. First and foremost, it requires the active engagement of participants in the key decisions about the research trajectory and research design as well as in all of the analytical components. Participatory approaches are relevant for implementation and scaling up not only in terms of generating data, but also because participatory methods generate internal learning by different stakeholders – including beneficiaries – which can enhance political and social sustainability. The following are key characteristics of participatory research:

The **research process should benefit those engaging in the research process** as well as others seeking to gain knowledge from the research. This can complement and enrich well established ethical principles in research of **beneficence** and **autonomy**: research must make a positive contribution towards the welfare of people and respect and protect the rights and dignity of participants.

Participation should extend as far as possible throughout the research cycle: determination of research questions; research methods; research design; data collection; data analysis; proposed solutions and action. Some so-called participatory research is little more than a way of getting local people to do data collection for researchers. When the participatory label is used in situations where local people feel that they have to engage in processes over which they have little if any control it can be 'a new form of tyranny' (Cooke and Kothari 2001)

Sometimes questions may reasonably be framed by outsiders, but in this case they need to be genuinely owned by participants to be seen as participatory. Similarly, participatory facilitators may know from past experience what research methods might be most likely to succeed, but participants have to understand those methods, and want to adopt them. These requirements imply that participatory research in health systems will typically necessitate a long term active engagement by researchers with in-depth knowledge of the local situation.

Participatory research recognizes multiple perspectives. The stakeholders engaged in participatory research should represent different (interest) groups in a health system, including those in need of services from the site in the country where the implementation takes place. Who should be involved depends on the questions that are being asked. Mapping techniques (Barker 2013) are often used to determine the key stakeholders and the power relations between them. Participatory research is based on discerning the appropriateness of interventions through triangulation of the multiple subjectivities of these diverse stakeholders. It is critical of universal claims about reality. Rather, it is based on an assumption that medical and social realities may differ and that effective health interventions also need to take social realities into account. Health experts, for example, might use positivist methods to test the efficacy of a vaccine, while more participatory methods are used to assess the appropriateness of the intervention to the population and the efficacy of implementation.

It has long been established by medical anthropologists that health care problems such as patient dissatisfaction, inequity of access to care, and spiralling costs are often not amenable to traditional administrative or biomedical solutions (Kleinman et al. 1978). Failure to take local realities into account often results in poor outcomes from investments intended to improve population health. Long distances to newly installed water points can put young girls and women at risk of sexual violence (UNHCR 2015). Lack of perceived ownership may result in the dismantling of expensive new sanitation blocks for parts. In many instances, the best technical solution is not necessarily the best social solution (Burns and Worsley 2015).

Ethical participatory research recognizes power and diversity Rather than assuming 'universal' western models and philosophies of health care and health systems, participatory research acknowledges power relations and the implications of the historical diversity of practices within countries. This encourages critical reflection and supports meaningful implementation of ethical research principles such as informed consent. A focus on individual rights and consent in health system research, for example, can be meaningless in cultural contexts where strategic life and health-related choices and decisions are made in a familial and/or community context (Oosterhoff et al 2008; Oosterhoff 2009). When people feel they are under economic pressure, it can cause them to participate for financial reasons (Lindegger et al. 2006). Without such a proper understanding of local contexts, research may serve mainly to reinforce institutional and structural power inequalities rather than operate in the interests of either subject or researcher.

Similarly, **participants in participatory research do not regard themselves as separate from the subject of the research**. As Loewenson et al. (2014) point out, Participatory Action Research:

> "transforms the role of those usually participating as subjects of research and involves them instead as active researchers and agents of change. Those affected by the problem are the primary source of information and the primary actors in generating, validating and using the knowledge for action" (Loewenson et al. 2014:12)

3.   Is participatory research always qualitative?

Sometimes people position participatory research as a form of qualitative research that is in opposition to quantitative research. This is not the case. The defining issue for participatory research is who decides what data to collect and who analyses and interprets that data – not what sort of data it is. What follows from this is that while there are a number of specific methods that have been particularly associated with participatory research, a wide variety of data collection methods, including sample surveys, focus groups, key informant interviews and ethnographic studies, and a similar range of analytical approaches, for example statistical modelling and thematic analysis, can be integrated into a participatory research process.

Research methods that are commonly associated with participatory methods include:

Peer research – where researchers are trained to support a group of individuals like themselves to generate data, undertake analysis and produce outputs. This is particularly useful for vulnerable groups who are unlikely to 'open up' in the presence of 'authority figures'.

Example: In 2003 Burns and colleagues supported a facilitated research process with young people in Hounslow (Percy-Smith et al. 2003), an area of relative deprivation in London. They worked with the local community health council to identify people in the area from a range of very different settings and backgrounds. They trained this core research group in participatory inquiry approaches. Each of the groups then went back to their communities and explored what the key health issues were. The groups produced a range of outputs using various creative methods including poems and story boards, as well as more traditional analytical techniques. The groups were brought together into a learning workshop alongside grass roots practitioners (including teachers, midwives and health visitors) and senior managers (for example, Directors of Education and Health services). They were able through visual methods (see below) to collectively identify priorities that could be fed into the development of local health policy. This research "challenged health professionals to reflect on their own assumptions and practices in response to the complex health concerns of young people and the need to connect more effectively with the real lives of young people in research and policy development. The collaborative action enquiry approach used models an 'alternative' and arguably more effective approach to policy learning involving young people, providing further evidence of the value of action research in health sector research" (Percy-Smith 2007:891)

Action Research – There is a long history of Action Research which ranges from reflective practise with an individual focus (which has a strong history in nursing practice – for examples see Vallenga et al. 2009) to co-operative inquiry with a group focus; to Participatory Action Research (Baum et al. 2006) (which tends to have a community focus – for examples see EQUINET: TARSC and ALAMES 2014) and Systemic Action Research (Burns 2014a, Burns 2014b, Burns 2007). Action Research traditionally involves a process where groups explore issues in a cyclical way: starting by assessing the situation; then planning; then taking action; then assessing the effect of that action; in the light of this reassessing the situation; and so on. Action research in health systems can adopt both participatory and non-participatory research methods. In North East India a group of international and national public health researchers looked at the opportunities for indigenous Khasi women to participate in health policy making in the area of Sexual and Reproductive Health and Rights. The research methods included both non-participatory methods such as desk research, individual and group interviews by local indigenous researchers, and digital story telling (Oosterhoff et al. 2015a).

Key in the approach was that the results were shared with many stakeholders, both policy makers and local Khasi women's groups, as part of a joint analysis.

PRA (Participatory Rural Appraisal) methods – Rapid appraisals are well established public health tools in a wide range of development and emergency settings (UNHCR, WHO 2008; Needle et al. 2003; Annett and Rifkin 1995). In particular, they will often be used in contexts requiring Rapid Appraisal and Response (RAR), a terminology used to highlight the need for timely effective action in response to the findings of such an appraisal. Note that it is quite common for rapid appraisals to employ local or marginalized groups such as young people, drug users or urban slum dwellers. That does not necessarily mean they are participatory – unless these people are also involved in the analysis of the results. Genuine participatory research approaches must enable local people to identify their own priorities and make their own decisions about actions that should be taken based on the results. A range of methods for rapid appraisal were developed by Robert Chambers (1981) and others in the 1980's. They can include tools such as transect walks, participant observation, mapping, preference rankings, Venn diagramming (chapatti diagrams), village mapping, body mapping, life stories, counting and classifying essential and commercial medicines within households, and approaches that work with mystery patients or consumers (Mohanan et al. 2015).

Visual and performative participatory methods – include participatory video, digital stories, photo-voice and participatory theatre for development. Visual methods are a good way of identifying what really matters to people, triggering emotional responses, opening up dialogic inquiry into issues, and communicating effectively what the issues 'look like'. For example, a photo-voice exercise on the prevention of HIV and AIDS in South Africa uses photographs of a crowded taxi to show where the dangers of transmission lie in day-to-day life. Similarly, they show pictures of buildings without windows which make visceral the realities of the health environment (SLF, 2015). Theatre for Development in Nigeria is:

> *"increasingly used to explore health problems and their causes, for example in reproductive health. It recognises the inherently conflictual nature of interests, relations, and power around some of these issues. The dramas not only serve as codes for collectively identifying health risks and determinants, they also contribute to the shift in power relations needed to address these determinants or to support demand for or uptake of services. The process of building the drama often simulates collective conflict, to facilitate reflection by those who have power as well as to empower those who lack it"* (Cornwall and Jewkes 1995).

Participatory mapping includes: systemic causal mapping – which might be used to show the causal dynamics of how disease is spread; GIS neighbourhood mapping – which can be used simply to show the location of health facilities and catchment areas, or as a dynamic digital tool identifying hotspots in patterns of disease or accidents (Burns and Worsley 2015, Tatern et al. 2012, Emch et al. 2012), and social network mapping – which might be used to support discussions about how behaviour change might spread (Igras et al. 2016). Social mapping can also be used as an underpinning for participatory statistics, both to collect data and as a way to display or organize an analysis (Oosterhoff et al. 2016).

Participatory statistics. Many participatory processes will generate numbers, for example rankings and counts, and there will often be a joint analysis – involving multiple stakeholders – of the numbers collected. However, they typically make limited use of traditional statistical methods. Researchers adopting an approach which has come to be called 'Participatory Statistics' (Chambers 2007, Holland 2015) may in addition use standard statistical principles

such as probability sampling frames and statistical power calculations to sample and code data which can be non-participatory but is rooted in a participatory process. For example, local people may collect health data at village level, which they analyse and interpret before it is aggregated, following standard statistical procedures, for analysis at higher levels (Riemenschneider et al. 2013).

4.   How might participatory research be relevant when changes in the delivery or financing of health services are being proposed?

Participatory research methods allow technical knowledge to be integrated with local social knowledge in a deliberative process which enables effective intervention strategies to be developed. They can be used in many disciplines by various professional groups that study health systems: medical doctors, nurses, patient organizations, medical anthropologists and other social scientists.

There is a wealth of research, for example, on the low uptake of sexual and reproductive health services due to a lack of understanding of social and cultural realities. One instance relates to an international project aiming to improve maternal health among the Black Thai, an ethnic minority group in Northern Vietnam, which failed to recruit 'traditional birth attendants' because they assumed these would be women. Among Black Thai it is actually the men who – together with close family or neighbours – traditionally assist women with child birth (Oosterhoff et al. 2011). In North East India, national health policies made in the capital led health providers to provide contraceptives to indigenous Khasi which were not only medically dubious – if not harmful – but socially unacceptable (Oosterhoff et al. 2015b).

When changes to health services are introduced, participatory methods can help to understand where these should best be made in order that people will actually use them. For example, to plan for HIV and AIDS related referral systems in Vietnam, health managers, practitioners and people living with HIV (PLHIV) were asked to draw up maps to show what services people with HIV used. The maps of the three groups were totally different. Health policy managers assumed for example that people would use free testing services close to home. PLHIV however said that anonymity and speed of test results were their main criteria. The services they actually went to were literally not on the map of the health service providers.

Participatory research can also help to assess if any change should be made. Vietnam had an opt-out HIV testing service when global policies, including that of WHO recommended offering anonymous and opt-in testing. Opt-out was seen as compulsory and possibly a violation of human rights. Action research actually showed that opt-in testing was not preferred because it would require patients to ask for it and health staff to offer it to some – but not all – patients. Both health staff and patients wanted to avoid the stigma and shame attached to the disease, which was seen as less of a problem under an opt-out service (Oosterhoff et al. 2008).

Participatory approaches can also help management to understand and detect differences in service provision, and set priorities. The authors have used participatory approaches in health policy work (as discussed in the Hounslow example above) and public health leadership work. For example a year-long action research programme with Directors of Public Health explored the decisions and dilemmas faced by senior managers in health. This group learning process bought to the surface a huge diversity of approaches and priorities of public health leaders and enabled them to learn from each other. (Burns et al. 2004a; Burns et al. 2004b).

Loewenson et al. (2014) cite a wide range of examples of the uses of Participatory Action Research in Health Systems. For example: Generating risk maps in a steel mill in Mexico; building a community-based child health information system in South Africa; analysing narratives from community outreach workers in Chicago; developing a participatory poverty index in China; participatory 'pharmocovigilance' to identify and evaluate previously unreported adverse drug reactions in Uganda; and community research to support primary health care in Zimbabwe. The extent of the examples, and the co-publication of this book by WHO, indicates a widespread recognition of the value of participatory studies alongside more mainstream health research.

What participatory research methods might be most appropriate?

There is a wealth of information available on participatory methods in different contexts. As it is an approach that can be used in many disciplines, and there are dozens of ways of classifying and categorizing methods and tools, it is worthwhile to have a fairly clear idea about the question that one wants to address before starting an internet search. A lot of tools are just about collecting data with beneficiaries who may participate in feedback meetings or consultations, but will not be involved in the analysis. A useful place to start is the participatory methods website, which provides resources to generate ideas and action for inclusive development and social change, including in the field of healthcare. A participatory approach to communities infected and affected by HIV and to PLHIV and their support groups has been key in HIV and AIDS research. See, for example, UNAIDS and Royal Tropical Institute (2004). If you would like to know more about action research and participatory networks you may also want to look at the ALARA network.

5.   The use and value of participatory research

While participatory research has had a long tradition of generating rich data for local 'meaning making', the process by which individuals interpret their situation, relationships, events, etc., it has struggled against the critique that its analysis is only of value in a specific local context and cannot be used to draw more generalised conclusions. Over the past 10 years or so methods have advanced considerably (Burns and Worsley 2015). Systemic Action Research (Burns 2014a, Burns 2014b, Burns 2007) enables multiple inquiry streams to operate in parallel across a wide geographical terrain; collective analysis processes (Easpaig 2015) allow large amounts of narrative data to be analysed by local communities within a matter of days rather than weeks; participatory statistics enables verification of emerging hypotheses in ways which mirror those used in the analysis of traditional sample surveys.

In the example that follows we show how the use of a participatory methodology within a multi-method research programme on slavery and bonded labour opened up profound questions about local health systems (Oosterhoff et al. 2016). Experience derived from the research programme can be used to illustrate: (a) how participatory methods can be used at scale; (b) how mixed participatory methods generating both qualitative and quantitative data can be used to support and triangulate each other; and (c) how significant health issues can be revealed through such participatory processes.

Slavery and Bonded Labour in Northern India: A case study of mixed methods participatory research

Since 2014, the authors have been co-directing a research programme to provide data and analysis in support of NGOs and others working to combat slavery. Modern slavery can take many forms and there are many definitions. That adopted by the Freedom Fund, a

philanthropic initiative dedicated to the fight against modern slavery and a partner in the programme, is that that individuals in slavery: are paid nothing or below subsistence wages; cannot walk away; and are subjected to violence or threats. More generally, they are used, controlled and exploited by another person for commercial and personal gain.

The slavery work is in three intervention sites. Two are in India: one in Uttar Pradesh and Bihar, focusing on brick kilns, stone quarries and sex work; and one in Tamil Nadu, focusing on cotton mills. The third is in the South Western Terrai, Nepal, and focuses on agricultural bonded labour. Although the same research design has been used in each, here we discuss the Northern India research.

This has three building blocks:

(1) Life story collection and collective analysis using the techniques of participatory clustering and causal mapping
(2) Participatory statistics
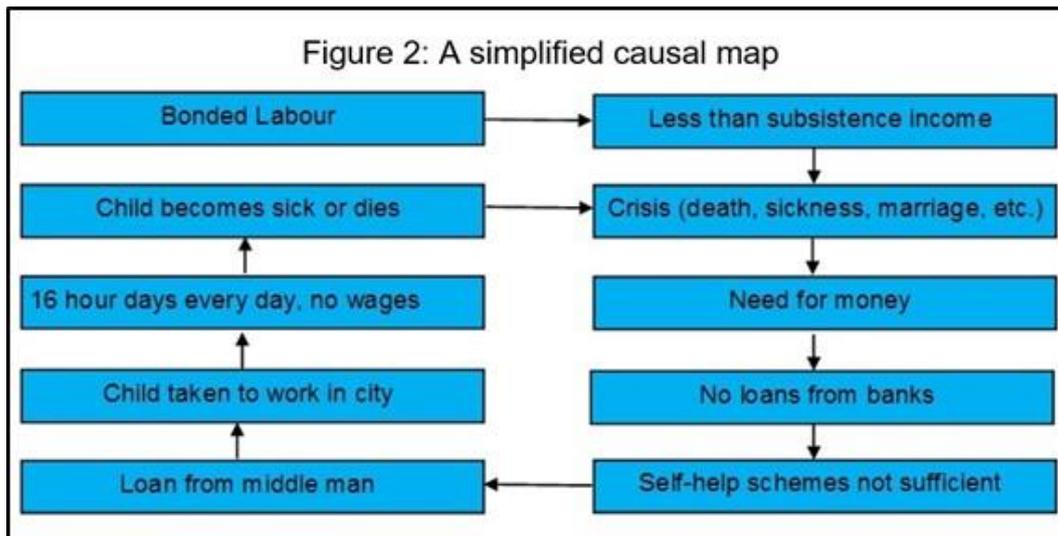(3) Action Research

These three are interconnected. Over a period of approximately three months, each NGO collected some 44 stories from the villages where they worked, resulting in 355 stories. In each village they collected seven stories of people who were assessed as being in slavery, two from people who had been at risk of slavery but avoided it, and two from leaders or professionals in the village who had some insight into the slavery situation. Prior to story collection, grass roots NGO workers were trained how to encourage people to tell their stories in ways which would not tend to bias those narratives, and how to ask follow up questions which deepened the issues which the story tellers had raised.

The collective analysis workshop allowed analysis of 353 life stories over 4 days. First, participants were divided into pairs. Each pair had approximately 20 stories to analyse. They were given simple questions. What is the primary message that this story is telling us? What are the most important factors in the story and why? A participatory clustering exercise was then undertaken. The major themes identified for each story were shown on a board and participants co-related similar themes. The findings from this exercise were that there were over 50 stories which focused on loans for health and a further 20 which focused on other health related issues. Participants were then instructed in the basic concepts of causal mapping and asked to construct a 'causal map', to plot what they saw as the causal links between the various factors associated with slavery, using the evidence from the stories they had analysed. This was a collective activity involving all participants and the map, covering some 20 sheets of flip chart paper, was displayed on a wall in order that everyone could follow its construction and contribute.

Figure 1: The causal mapping process in action

The causal map revealed a pattern which was essentially as follows. People who live in bondage have little or no money because they receive below subsistence incomes. When they hit a health crisis they need money to pay for care. Because the banks will not give money to slaves, and the local credit and loan schemes cannot provide enough, they have to go to a middle man who will broker a loan (often from a land owner) at interest rates of 60-120% per year. Because they have no money, they guarantee their own or their child's labour for two to three years to pay back the loan – either directly to the money lender or to an associate. The work is often physically hard and hazardous labour carried out with little protection, leaving workers prone to accidents. Poor food and housing conditions also increase the risk of disease. Both may lead the family to need additional money for health care, deepening and prolonging indebtedness.

Figure 2: A simplified causal map

Bonded Labour	→	Less than subsistence income
Child becomes sick or dies	→	Crisis (death, sickness, marriage, etc.)
16 hour days every day, no wages		Need for money
Child taken to work in city		No loans from banks
Loan from middle man	←	Self-help schemes not sufficient

The vicious cycles and structural interactions between poverty and ill-health are well known (Aslan 2007, WHO 2002, Farmer 2001, Scheper-Hughes N. 1993). Although in both Bihar and Uttar Pradesh the government has made the improvement of health a priority and is investing in the health systems, this is somehow not benefitting these very poor and marginalized communities. Most of them belonging to lower castes, and face well known stigma and exclusion in accessing services. When NGO participants were asked to indicate the issues on which their interventions were focused, we found three strong clusters of activity around (a) supporting collective action, (b) awareness raising and (c) linking people to public services. There were almost no interventions related to health and none related to health loans. The programme thus provided both the NGOs and the funder with insights as to the potential value in terms of their primary objective of interventions that could improve the health status of these communities. If ill-health could be shown to increase the risk of slavery for the overall communities with which they were concerned, it would imply that improvements in health status should be a priority in slavery eradication efforts. To verify the analysis of the life stories and understand if health loans and poor access to health services were widespread in the lives of the people in the targeted communities, the researchers used participatory statistics.

Participatory statistics has the potential to satisfy a key requirement for impact evaluation and scaling up: the ability to generate quantitative data that can endorse attribution – thereby responding to the accountability and learning processes that are important for political and social sustainability. In the current example, an open-ended bottom up approach to the development of indicators and definitions, based on the multiple narratives described above, was used to generate data which was then subjected to formal statistical analysis.

A baseline study was conducted which involved 3,500 chulas (households) in 87 villages. Randomly selected programme beneficiaries collected the data and analysed the results of the prevalence to take collective action based on the results. For example one group saw that dowry was the second reason after health why people get into debts that lead to bonded labour and asked the NGO to pilot a program with free marriage parties for couples who marry without a dowry. Within months a few couples did get married without a dowry. This approach allowed us to scale up decentralized, open-ended and action-oriented participatory processes involving both beneficiaries and NGOs and generate the data for a survey across the programme with sufficient statistical power. A follow-up survey will be carried out two and a half years after the baseline (Oosterhoff et al. 2016).

The preliminary analysis of 10 NGOs in Bihar showed that slavery was indeed widespread. Around 46% of households had a member in slavery. Almost 70% of people had no access to state health services, both slaves and non-slaves, and the vast majority of loans, almost 60%, were for healthcare. Slaves had more loans than non-slaves (85% vs 57%). These results suggest that health problems and health expenses are significant factors in terms of increasing the risk of slavery in spite of investments in the health system and the promotion of universal health care. A better understanding of the nature of the health problems (accidents, acute illness, chronic illness), health seeking behaviour, including the use of private or informal providers, and health expenditures is needed. The findings suggested that continuing to 'up-scale' the existing health system strategies was unlikely to improve the health status of those in the targeted communities.

6.   Conclusion

The evolution of participatory methods has accelerated rapidly over the past 20 years. Many participatory methods are now available which can genuinely engage stakeholders in the research process. These approaches can be used alone but as we can see they can also be effectively integrated with more traditional approaches such as statistical analysis. Because there are now effective methods to take them to scale they can be more systematically embedded in health policy design and programme scale up and learning strategies. Participatory Research is crucial when operating at the interface of medical and social systems – where norms, culture, power, resources etc. become critical variables in determining what is appropriate, relevant, effective and implementable.

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