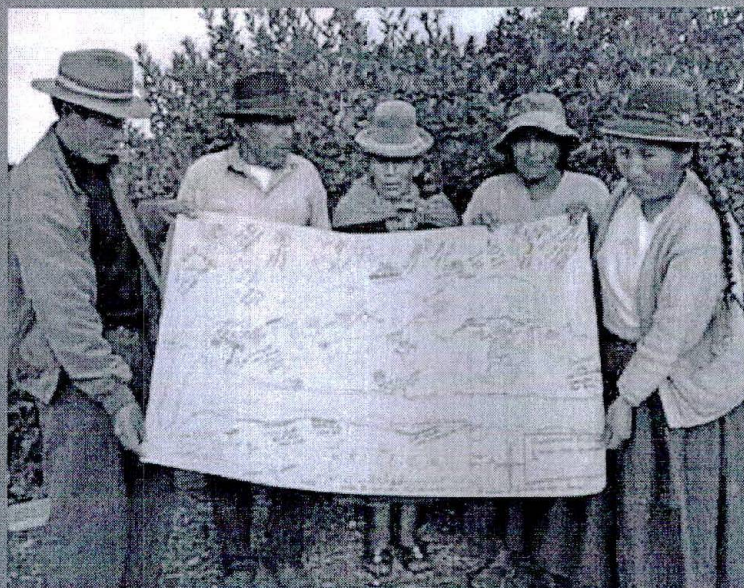


# PARTICIPATORY ACTION RESEARCH in health systems

## A METHODS READER



Rene Loewenson, Asa C Laurell, Christer Hogstedt, Lucia D'Ambruoso and Zubin Shroff



Regional Network on Equity  
in Health in East and  
Southern Africa



Training and Research  
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Alliance for  
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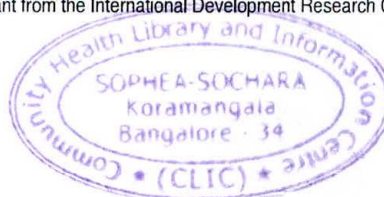
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# About the reader

*If you have come to help me, you are wasting your time, but if you have come because your liberation is bound to mine, then let us work together.*

Lila Watso, Aboriginal woman leader

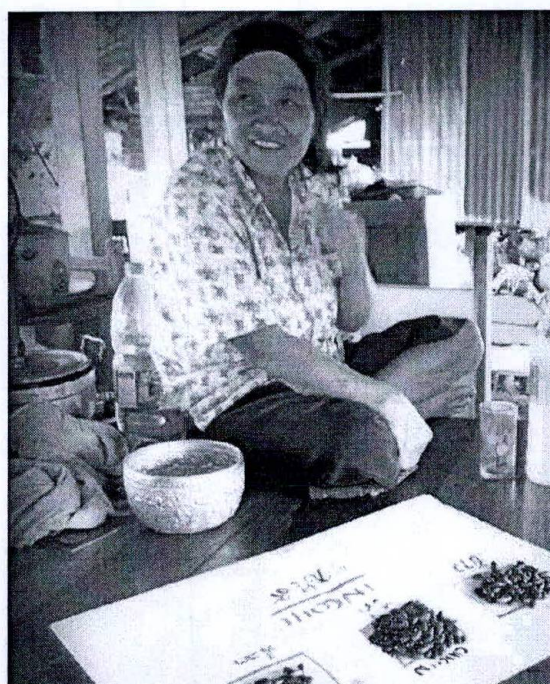
## Why do we need this reader?

We produced this methods reader to inform, motivate and strengthen the practice of participatory action research.

Dr Bill Foege, former director of the Centers for Disease Control in the United States (USA) summed up the 20th century in health as a time of spectacular progress and spectacular inequities (cited by Tim Evans in Loewenson, 2013). In the 21st century there is a growing demand to channel collective energy towards justice and equity in health, and to better understand the social processes that influence health and health systems. Communities, frontline health workers and other grass-roots actors play a key role in responding to this demand, in raising critical questions, building new knowledge and provoking and carrying out action to transform health systems and improve health.

There is a widening array of methods, tools and capacities – old and new – to increase social participation and power in generating new knowledge through participatory research. At the same time, we need to be clear about exactly what participatory research is and what it can offer. The term ‘participatory’ is often loosely used to encompass a wide range of different research methods and ways of reporting research. The methods are not always well understood by those using more experimental approaches. This reader promotes understanding of the term ‘participatory action research’ (PAR) and provides information on its paradigms, methods, application and use, particularly in health policy and systems.

Much excellent material for community level participatory action research training is already available. To avoid duplicating these resources we give detailed outlines of the methods and direct attention to these available materials at different places in the text. This reader seeks to demystify participatory action research in health policy and systems research. It explores the various roles this research can play in improving health and health systems and is particularly useful for academic, health system, policy and social communities working in this field. This reader thus seeks to clarify the methods used in both health policy and systems research (Gilson, 2011) and in implementation research (Peters et al., 2013).



*Use of proportional piling to discuss households' revenues and the importance of livestock in Thailand*

© Grease network-CIRAD-Thailande/ Sophie Valeix

### What are the aims of the reader?

This reader thus seeks to explain:

- key features of participatory action research and the history and knowledge paradigms that inform it;
- processes and methods used in participatory action research, including innovations and developments in the field and the ethical and methods issues in implementing it; and
- communication, reporting, institutionalization and use of participatory action research in health systems.

As a tool to support understanding and learning, the reader uses explanatory text backed by references and resources. It includes examples of participatory action research across high, medium and low income settings and across all regions globally. It provides a selection of readings on the subject (in *Part five*).

### Who is the reader for?

The reader is aimed at a wide audience:

- the academic and research community;
- the health policy and systems research community;
- health workers and managers in health systems;
- community level organizations, including trade unions, health activists and health promoters; and
- policy actors.



Villagers draw a map of their area to identify areas where environments pose a risk to health, Malawi

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## **The structure of the reader**

The reader is organized in five parts. This first section introduces the reader and its aims.

### **Part one: Concepts**

This part gives an overview of participatory action research and its use in health systems and in health policy and systems research, summarizing the key features and the historical roots and drivers. We describe the different participatory action research paradigms used to generate knowledge and explore the significance of a paradigm that locates the nature and production of knowledge as an outcome of social relations. We discuss the role of power and participation in health systems as a context for participatory action research, relating it to other forms of health policy and systems research (HPSR).

### **Part two: Methods**

This part focuses on implementing participatory action research in health systems, introducing the processes and methods used, including those to overcome the subject-object distinction. We suggest methods and tools for gathering evidence, noting the importance of context. We explore some specific aspects of implementing participatory action research, including the use of new information technologies, the methods for reviewing, reflecting on and evaluating action and for meta-analysis across individual sites. Finally we outline experiences on institutionalizing participatory action research in health systems.

### **Part three: Issues & challenges**

This part raises various issues that arise in applying these methods in participatory action research, including selection bias, classification and comparability of groups, validity of evidence, causality, and reproduction and generalization of results. We examine ethical issues and logistic challenges, as well as the opportunities this approach offers in health policy and systems research.

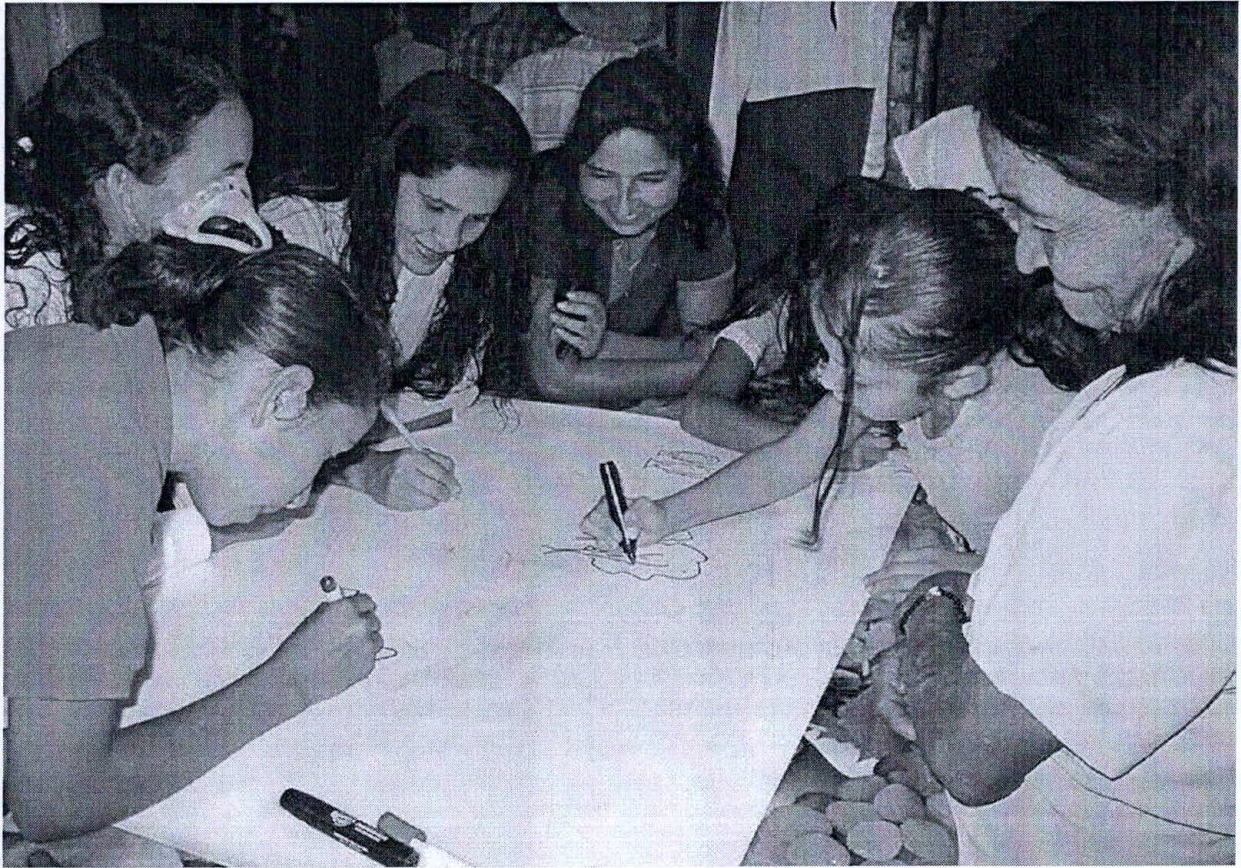
### **Part four: Evidence & action**

This part discusses options for and experiences in communicating and using evidence from participatory action research, offering guidance on reporting. We discuss how to use the knowledge generated in participatory action research in health systems and policy. Finally we explore the role of learning networks and communities of practice in supporting and developing participatory action research methods and practice.

The references used are listed at the end of *Part four*.

### **Part five: Empirical papers**

This part in the web version provides links to twenty-one published empirical papers that are referred to in different parts of the reader and that provide examples of different features and aspects of participatory action research. Wherever a paper in Part five is referred to in the text, the paper number is included for easy reference.



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# **Part one** **Concepts**

*Part one cover page photo:*

*Women drawing a social map of the impact of climate change in their area, Colombia  
Men and women worked in separate groups to explore differences in their perceptions  
of these impacts*

# Part one

# Concepts

## 1.1 Key features of participatory action research

This section introduces the key concepts used in the reader, including those relevant to health systems, research, health policy and systems research and participatory action research. Each of these concepts is dealt with in more detail in later sections.

Much attention has been given to establishing and acting on physical and biological determinants in medical sciences and systems. The focus has been on immediate determinants of ill health (water, food, work environments) in public health. However, people's chances of being healthy are also increasingly acknowledged to be shaped by social structures and systems. Understanding the immediate risk factors for ill health in individuals has had an important but insufficient impact on changing the distribution of health in populations, as well as on addressing inequalities in health and knowing what helps people stay healthy, as opposed to what makes them ill. The 2008 report of the Commission on the Social Determinants of Health (CSDH) presented a significant body of evidence showing that social processes and differentials in power and resources contribute to health outcomes. They affect how resources for health and health care are allocated to, reach and are used by different social groups (WHO CSDH, 2008).

Health systems play a role in this. Not only do they impact on health outcomes but they are themselves social systems that reflect or confront and shape wider societal norms and values. They do not *on their own* affect these social differentials and processes that affect health. Health care systems, as social institutions, are built out of existing

social structures. They reflect social inequalities but can also confront them. For example, people-centred health systems and comprehensive primary health care approaches can lever inter-sectoral action, support social cohesion and empowerment and tackle differentials in resource allocation and people's access to, use and experience of health care (Loewenson and Gilson, 2011).

Health systems can, in the way they function, strengthen the capabilities of individuals and social groups, for example, by including opportunities for people to participate in planning services, from individual care plans to community health interventions. They can generate preferential gains for socially-disadvantaged groups, either by impacting on the structural factors that disadvantage them (such as in promoting women's autonomy) or by strengthening their ability to claim health resources or implement health actions (such as by involving them in participatory mechanisms for planning and budgeting) (Loewenson and Gilson, 2011).

**Health systems** and the institutions, actors and processes within them seek to promote, restore, or maintain health, to fulfil obligations and claims on universal rights to health and to health care. Their role is further discussed in *section 1.5*.

**Social empowerment** refers to 'people's ability to act through collective participation by strengthening their organizational capacities, challenging power inequities and achieving outcomes on many reciprocal levels in different domains: including psychological empowerment, household relations,... transformed institutions, greater access to resources, open governance and increasingly equitable community conditions' (Wallerstein, 1992).

Health systems can thus play a role in the social empowerment, agency and capabilities needed to improve well-being. This is not merely a matter of making services, personnel and commodities available. It relates to how systems organize public information and participation in decision-making, and invest in relationships, communication, knowledge, leadership and capacities to support these roles and functions (Loewenson and Gilson, 2011).

However, health systems do not always do this; they are also spheres of private profit and may reflect and not confront differentials in power and resources. Even in not-for-profit services, power differentials exist between different groups of health workers and people. Disempowerment and social exclusion are

determinants of health and can lead to vicious cycles of inverse care, where those who most need health care have lower access (WHO CSDH, 2008).

By collecting, analysing and interpreting evidence, research provides new knowledge to inform pathways and policies to improve how health systems function. Research is motivated by contradiction, such as that between how things are currently understood and how they are in reality, between what exists in reality and what is desired or between different views or analyses of the same reality.

Health policy and systems research, discussed further in *section 1.6*, is one source of such new knowledge. It is characterized not by any particular methodology but by the types of questions it addresses, for example, on implementing services and on the roles, interests and values of key actors in shaping policies and services.

The term 'participatory research' is applied to a wide range of research approaches, with different people interpreting it differently. The term is sometimes used to describe practices where the participation by those affected is actually very limited. This reader does not cover this wide spectrum of meanings but rather focuses on participatory action research as defined in the box on the left, and looks at the way it is used in health policy and systems.

Participatory action research recognizes the wealth of assets that community members bring to the processes of knowing, creating knowledge and acting on that knowledge to bring about change. This section discusses how participatory action research can potentially contribute to health policy and systems in the following ways:

- Researching and answering questions that are important to communities and that help us understand the social determinants of health and the way social roles and relationships affect the uptake and performance of health systems;
- Strengthening communication and mutual respect among those involved in health systems, including those in disadvantaged and vulnerable communities;
- Bridging the gap between knowledge and practice by embedding problem solving and action in research methods;
- Enhancing the credibility of research findings by supporting capacity, involvement and activism among those directly affected by health issues;

**Research** is generally understood to be a process that generates new knowledge and understanding. Some definitions include that the purpose of this understanding is to stimulate action and achieve change.

**Health policy and systems research** aims to understand and improve how societies organize themselves to achieve collective health goals and how different actors interact in the policy and implementation processes to contribute to policy outcomes. By its nature, it is inter-disciplinary. It blends and applies economics, sociology, anthropology, political science, epidemiology and other spheres of public health to draw up a comprehensive picture of how health systems respond and adapt to health policies, and how health policies can shape – and be shaped by – health systems and the broader determinants of health.

Source: Alliance for Health Policy and Systems Research website, October 2013

**Participatory action research (PAR)** has several key features.

Firstly, it transforms the role of those usually participating as the subjects of research and involves them instead as active researchers and agents of change. Participatory action research aims to *overcome the separation between subject and object*. Those affected by the problem are the primary source of information and the primary actors in generating, validating and using the knowledge for action. The researcher is thus part of the affected community, a facilitator of empowering processes in the affected community or directed by the affected community.

Secondly, it *involves developing, implementing, and reflecting on actions* as part of the research and knowledge generation process. Participatory action research seeks to understand and improve the world by changing it, but does so in a manner that those affected by problems collectively act and produce change as a means to new knowledge.

Source: Loewenson Laurel and Hogstedt (1994); Baum et al. (2006); Loewenson et al. (2011; Part five paper 1)

- Improving health systems, for example, by detecting health problems early and acting on them, by organizing person and population centred health services and by strengthening the social accountability of health systems.

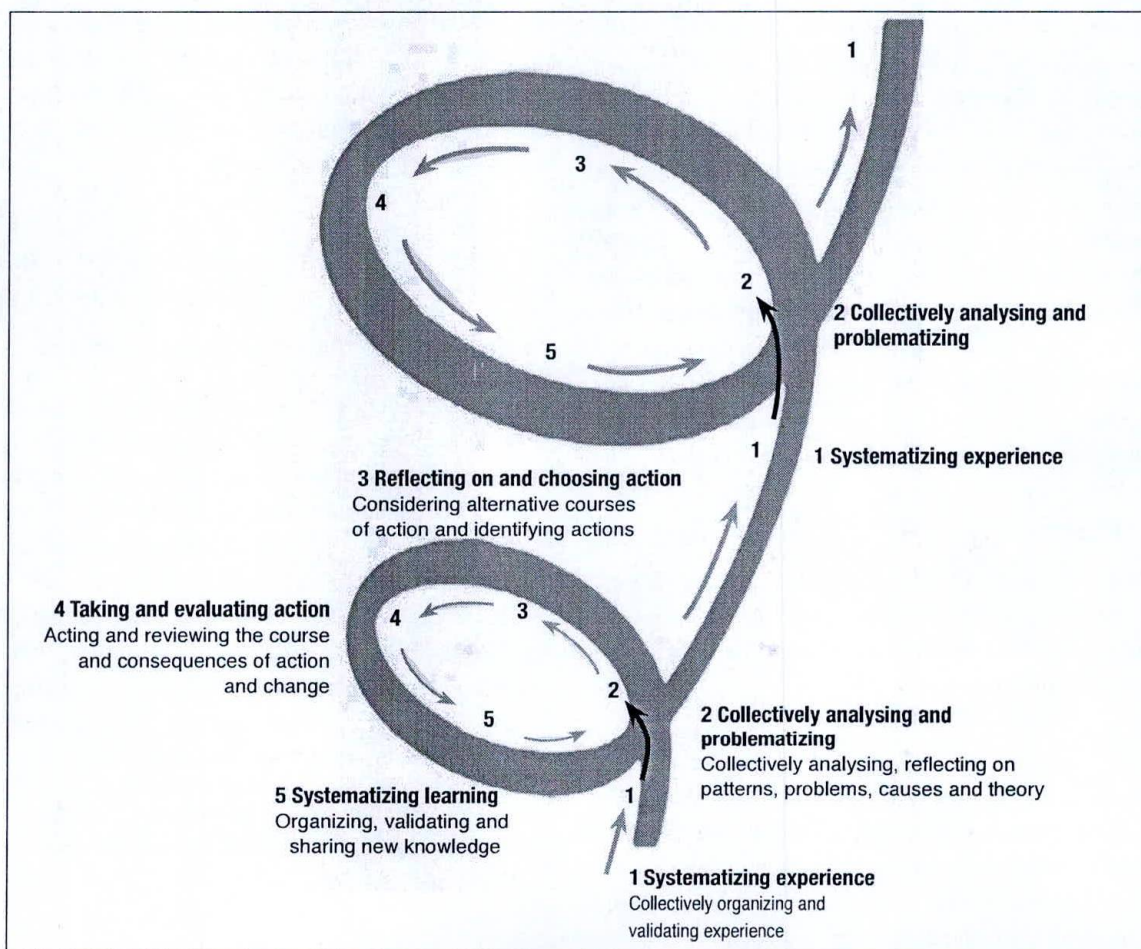
The community is the unit of identity, solutions and practice. 'Communities' are understood as groups with shared interests or culture in participatory action research and, while sometimes geographically located, they are not simply geographical or administrative groups. People living within a particular locality frequently have different economic circumstances, social interests, norms, experiences and problems as well as different access to resources.

In hierarchical societies, people who have been disadvantaged and disempowered may not be immediately obvious or accessible, and local forces within the community may block their voices. In later sections we discuss how participatory action research organizes its methods around groups that are more homogenous with respect to their interests and

experience and how these methods address differences or conflicts within different interest groups from the same area or group of people. We also raise the need for specific, proactive measures to reach and include those most disadvantaged.

The methods systematize local experience and organize shared collective analyses of the relationships between problems and their causes. The process of reflection is directly linked to action. It is influenced by an understanding of history, culture and local context and is embedded in social relationships. Reflecting on and analysing experience, perceptions and actions generates new learning and knowledge. As a first step, those initiating participatory action research often start by obtaining an insight into the communities and their conditions. This provides the information to support inclusion in the work, to systematize experience and to draw out priorities for attention. Later, in repeating cycles of work in the same community, new issues may emerge from reflecting on learning from action.

**Figure 1: The cyclical and spiral process of participatory action research**



Source: Authors

Participatory action research is based on a recognition that practical experience is an important source of knowledge that can be transformed into scientific knowledge through different procedures to systematize and validate the experiences. The process for this is shown in Figure 1 on page 13 and is discussed in greater detail in *Part two*.

The participatory action research process is a spiral of repeated cycles, where the experience of and learning from action and transforming reality becomes the input for a new round of collective, self-reflective inquiry, drawing in wider relevant knowledge from other sources to inform analysis and action.

### Qualitative and quantitative evidence

Whether evidence is qualitative or quantitative is not an issue. Both forms may be collected extractively – being gathered and removed for analysis – or may be collected in more participatory ways. Participatory action research generates and organizes both kinds of evidence to produce knowledge, as discussed in *Part two*.

While some people regard the knowledge from participatory methods as less scientific, research rigour and validity are as important in participatory action research as in any other, as discussed in *Part three*. However, the way this is achieved differs. The work uses collective approaches to validate data and ‘broadens the bandwidth of validity’ with respect to research relevance (Minkler et al., 2010). Participatory action research produces knowledge for the scientific community *and* for society, establishing a dialectic in which both social groups and the scientific community have a role in producing and appropriating knowledge. Involving social groups and health workers in producing evidence and learning can strengthen the legitimacy of research findings (Loewenson et al., 2011).

These features, the change in subject-object relations and the role of reflection on experience and action as a source of knowledge point to two other features of participatory action research.

### Shifting knowledge and power

Participatory action research aims for a change in societal power as the control of knowledge creation shifts towards those affected by problems. Associated with this, knowledge is produced by taking action, including in challenging social injustice.

The methods in participatory action research can affect the location of power at every stage of the research process. The process is sensitive to context and *shifts power towards those affected by the problem* in terms of how they collectively know, problematize, understand, act on and transform the conditions that affect their lives. The process of participatory action research should thus empower people, giving them increased control over their lives.

In so doing the design and process of participatory action research provides a means of *contesting power imbalances and transforming systems and institutions to produce greater justice*. This is justice in terms of fair opportunity and access to resources, fair procedure and recognition or respect. It responds to the reality that conditions of injustice are not natural but are produced and so can be challenged.

Emancipatory forms of participatory action research are argued to offer a means of expanding social agency and activism and of encouraging intellectual approaches. These approaches allow people to create counter-narratives to dominant characterizations that undermine them or their health. These counter-narratives facilitate systematic and institutional change and promote social justice (Cammarota and Fine, 2006). This is most likely to flourish where organized groups demand and create the conditions for this shift in control (Minkler, 2000 and 2005; Baum et al., 2006).

*Part three* discusses the methods for such emancipatory forms of participatory action research and the issues to address in implementing them.

### Increasing practice of participatory research

There is evidence that the practice of participatory research is increasing. Community participation is a basic principle of essential national health research that involves a partnership between three categories of actors: policy and decision makers, researchers and communities (Task Force on Health Research for Development Secretariat, 1991). Some countries have explicitly included the role of communities in research in their national policies (Australia National Health and Medical Research Council and Consumers Health Forum of Australia, 2001).

Three systematic reviews, one narrative review and two bibliographies of published work on public involvement in health research in the UK and USA between 1995 and 2009, for example, found 683 papers, including 417 empirical papers and 266

secondary reviews, in which a participatory or action research approach was dominant. While the range of what the reviews termed as ‘participation’ was wide, as discussed later, the evidence suggests increasing public involvement in research, with empirical studies consistently out-numbering literature reviews from 1998 (Boote, Wong and Booth, 2012).

Participatory action research is applied across many areas of health and health system functioning, from acting on social determinants and inequalities in health to transforming health services and improving their outreach and uptake. We present many examples of the use of this approach to research in health systems throughout the reader. In some of these examples, participatory action research is a *utilitarian* way to access evidence of the complex social dimensions of health systems. Its value is in producing evidence that may otherwise be hidden or difficult to obtain. Since it intentionally includes the experience and perspectives of marginalized people, it can strengthen the understanding of these social influences in health systems, making a connection between public actors and the political forces and technical actors that shape systems, institutional practice and public policy.

This approach has also been used in a *values-based emancipatory manner* to explicitly profile agency and social power in health systems. It provides a process for building knowledge in health systems within which public and civil society engagement, social power and active citizenship can grow. It does this in contexts of socio-political transformation or as a challenge to the growing social inequalities arising from shrinking public budgets and contracting public services (Fine, 2006; Kaim, 2013).

Other processes promote social involvement and activism in health systems. For example, *community-led initiatives for demand side accountability and transparency* can raise social demand on budgets, resource use and service delivery. Hence for example, communities monitoring medicine prices or use of public funds in local health services opens these areas to wider public scrutiny and challenges practices that do not respond to health needs.

Community-based research may capacitate and involve communities as researchers to carry out quantitative surveys and qualitative studies. While these are important processes in implementing participatory action research, they are not in themselves participatory action research. They may,

#### SEE PART 5: PAPER 1

Loewenson et al. (2011) give examples of participatory action research used in different dimensions of health systems functioning and in different regions.

for example, focus ‘downstream’ on how public funds are spent or services are delivered, in relation to commitments made, without questioning the knowledge base that established those commitments or whether the community helped shape them (Gaventa and McGee, 2013). Communities trained to do research may position themselves as ‘researchers’ and maintain the same subject–object distinction as more traditional research, not transforming control over knowledge generation. While accountability initiatives and community-based research may thus be implemented using participatory action research approaches, they do not always necessarily do so.

This reader provides information on the paradigm, process and methods for participatory action research, while noting that communities sometimes select more traditional survey or monitoring approaches as part of a wider research process.

## 1.2 Historical roots and drivers

There are different views documented on the origins of participatory action research. However its application in a range of disciplines, including in the health, agricultural, political and social sciences, points to common roots in questioning and critiquing the dominant paradigms for generating knowledge (Laurell, 1984). Two strands of participatory action research have emerged. One is a pragmatic or utilitarian approach, launched in Europe and the USA in the middle of the 20th century, along the lines of action research. The other is an emancipatory model, influenced by Paulo Freire and the pedagogy of the oppressed in the 1970s.

The pragmatic approach was motivated by the need for change. Involving communities was a way of ensuring change in areas where community perceptions and roles were critical. The emancipatory approach was ideologically and theoretically motivated, more explicitly recognizing and addressing the power relations, consciousness and collective organization that influence the production of new knowledge and its use in change (Loewenson, Laurell and Hogstedt, 1994).

## Action research

The 'action research' school emerged from the work of German social psychologist, Kurt Lewin, in the 1940s. Lewin's approach involved people affected by a problem in a cyclical process of fact finding, action and evaluation. Lewin first used the term 'action research' in his 1946 paper 'Action research and minority problems'. He described a spiral of steps involving planning, action and fact-finding about the result of the action. Action research gained resonance as scientific research methods and techniques became more sophisticated and were perceived as less applicable in solving practical, 'real-world' problems (Masters, 1995). Action research used a pragmatic approach where knowledge about or perspective on a social or organizational system was gained by acting on that system through iterative cycles of problem definition, planning, acting and evaluating. Lewin's work encouraged scholars after the Second World War to apply action research to problems of social violence, prejudice and injustice, such as in research done by the Society for the Psychological Study of Social Issues.

Cammarota and Fine (2006) note, however, that social scientists and social psychologists retreated from action research for social change in the 1950s, seeking refuge in the experimental laboratory, in reaction to McCarthyism and other pressures. In the USA, researchers revived the use of participatory methods in various areas of social engagement, for example, in relation to sex stereotyping in the workplace, IQ testing, the death penalty, affirmative action and other challenges to social injustice where critical research in community forums provided sites of activism for change (Cammarota and Fine, 2006).

By the late 20th century many epidemiologists and public health practitioners were dissatisfied with the limited risk-factor paradigm in public health that overemphasized and organized interventions around individual risk, excluding organizational levels of risk. This led to calls for health and disease to be studied at a population level within a socio-political context using qualitative and participatory research methods (Leung, Yen and Minkler, 2004; Breilh, 2011).

## Community-based participatory research

Community-based participatory research thus grew in public health, in recognition of the social context of disease and of the need to integrate participatory

and action elements that were perceived as lacking in contemporary epidemiological research. Community-based participatory research work increased in all regions globally and is particularly widely documented in health policy and systems research in the USA. It recognized the community as a unit of identity and aimed to facilitate a collaborative and power-sharing partnership between the community and researchers in all phases of research. It fostered co-learning on the multiple determinants of health. While community-based participatory research aimed to ensure rigour and validity it also sought to 'broaden the bandwidth of validity' with respect to the relevance of research (Minkler et al., 2012; Viswanathan et al., 2004). The involvement of communities was built into the research process, often to solve local problems or to generate knowledge. While the distinction between the scientist and the non-scientist was preserved, it involved a mutual respect for the particular expertise that each was bringing to the research process (Denis and Lomas, 2003). While community-based participatory research was collaborative and inclusive of communities, it did not shift control over the research to the communities involved.

## Rapid and participatory rural appraisal

Concurrently, a second stream was emerging. Rapid rural appraisal evolved in the 1970s in response to the biased perceptions derived from urban-based professionals and to the limitations and high cost of large-scale questionnaire surveys. While outsiders still elicited and extracted the information as part of the data-gathering process, rapid rural appraisal was rooted in local contexts and the knowledge produced was linked to feedback and action. Some researchers developed more participatory forms of this approach, termed participatory rural appraisal (PRA), with the idea that local people can and should conduct their own evaluation and analysis. Forms of diagramming and other methods were developed and used to build understanding of the complexity and diversity of farming systems and livelihoods (Chambers, 1994).

## Participatory action research

A separate emancipatory form emerged, termed participatory action research (PAR). Distinct from both participatory and rapid rural appraisal, it grew out of and was deeply linked to socio-political processes, such as the popular education movement in Latin America, Asia, and Africa. This form of research explicitly recognized the interrelationship

of knowledge and *power*, such as in how different actors are positioned in controlling the production and interpretation of knowledge. Its methods differed from its precursors in this respect as it built on local contexts and cultures. For example, in many traditional African cultures decisions affecting the community are made collectively, with processes for continuous consultation and consensus in line with concepts of collective personhood and collective morality (Byrne and Sahay, 2007).

At the same time, participatory action research was influenced by changes in those contexts. In the 1900s mass democratic processes for independence and 'liberation' dominated politics in many countries in the south. Excluded communities in these countries, even after political independence, perceived themselves as marginal and shut out from the process of creating and appropriating knowledge within the dominant scientific community. Equally there was a social expectation that knowledge should play a role in challenging injustice and transforming society.

In Latin America, Brazilian educator Paulo Freire gave deeper structure to this demand for emancipatory knowledge in the 1970s. He engaged marginalized populations of Brazilian peasants as collaborators, researchers and activists. The 'Christian grass-roots communities' (*comunidades eclesíásticas de base*) linked to liberation theology also played a role. Freire believed fundamentally that any meaningful social transformation would only occur in conjunction with everyday people. The pedagogy of popular education was designed to help ordinary people develop the literacy and inquiry skills to engage with the structures of power more effectively.

Participatory action research developed as the research arm of this movement, understanding critical inquiry as a tool for social change. The assumption was that if knowledge is a source of power in society, then to achieve change in any collective setting one must become part of the processes used in producing and distributing knowledge. Freire, Fals Borda and other scholars from countries in the south developed this approach as a direct counter to the often 'colonizing' nature of knowledge and research monopolised by universities. They recognized the 'different sets of interests and power relations' that linked academic researchers and the communities they study. This emancipatory participatory action research gained recognition in Latin America during the 1970s through the Symposium of Cartagena

on Critical Social Science Research in April 1977 (Morrow and Torres, 1995).

In the 1970s, Freire and Hall assisted the Tanzanian government in designing their educational programme and Hall, with other colleagues, spread participatory action research there (Hall, 1997). Feminist and post-colonial scholars added further conceptual richness to participatory action research (Maguire, 1987) as did the Italian workers' movement in its struggles to change working conditions and society.

In participatory action research on work-related health problems in the 1960s–1980s in Italy, Latin America and southern Africa, and in the international and national union movements, workers studied their own work and health as organized labour (Loewenson, Laurell and Hogstedt, 1994). They reportedly implemented this research to respond to violations of workers' rights around their health and safety and to address the poor recognition of work-related risks or ill health in existing knowledge or laws. They wanted to gain more control over working conditions and address workers' discontent with existing working conditions and relations (Oddone, 1977; Loewenson, Laurell and Hogstedt, 1994).

These studies in different countries raised both the consciousness and the social visibility of workers and led to legal and institutional change. The 'workers' model' used in Italy is described as an example in more detail in *section 2.3, Box 12*. This model emerged from and supported an upsurge in the labour movement in the autumn of 1969. It focused on workers' rights and demanded increased control over their working conditions and organization. It challenged the dominant power of capital in determining workplace organization, starting in the big factories in northern Italy and spreading to a variety of workplaces all over the country (Laurell, 1984).

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These papers show the use of participatory action research in one region in different periods of time.

Fals Borda (1987) reviews and analyses this approach in Latin America at a time of expanding development in the 1970s and 1980s.

Falabella (2002) discusses the use of this approach in facilitating and providing space for social processes and knowledge under military governments in later decades.

The process was facilitated by the *Statute of Workers' Rights* of 1970 that guaranteed workers the right to intervene at the factory level to protect their health and their psychological and physical integrity. This turned health into a major concern of the three main unions that organized a joint national conference on the 'Protection of Health at the Workplace' in 1972. Thousands of delegates participated, including factory councils and unions and professionals.

The 'genealogical perspective' is an example of more recent developments in this emancipatory form of participatory action research in Argentina, Brazil and other Latin American countries. This perspective aims to adapt the approach to post-totalitarian societies and particularly to support the transformation of institutions (Faria de Aguiar and Lopes da Rocha, 2007). Influenced by the philosophers Foucault, Deleuze and Guattari and by socio-analysis, it applies participatory action research to trigger collective interventions and produce the micropolitics of social transformation.

The methods respond to a criticism from the 1960s and 1970s, that participatory action research did not fully recognize that consciousness is an ever-changing product of society. It tended to emphasise class and class consciousness, disregarding other forms of power and interests. In contrast, the genealogical perspective recognizes that knowledge is produced in everyday social practices and focuses on the micro level. Participatory action research is used to problematize the changing power relations and social interests in the context of specific local struggles. It links experience and theory with the aim of transforming power relations at the micro level. As with action research, it locates knowledge as a product of action. In this case, however, the action explicitly transforms social relations, institutions and systems. Actions that transform everyday practices, as a starting step in Figure 1, combine with experience and are used to expose, reflect and build knowledge on the interest and power relations prevailing. The knowledge derived from this becomes the beginning of a new cycle of deeper and continuous transformation. The subjects of the research are those that participate in a given practice and they too are changed as a result of the reflection and knowledge obtained in the process.

At an institutional level, proposals for participatory democracy through cooperation and self-government interact with this form of research to weaken bureaucratic hierarchies and reduce divisions

between disciplines that fragment everyday life. In so doing the work seeks to transform existing institutions through local action and to structure new egalitarian practices and new relationships between people working at the same and at different levels of the institutions that impact on health (Faria de Aguiar and Lopes da Rocha, 2007).

While both streams of work (action research, participatory rural appraisal and community-based participatory research on the one hand, and participatory action research on the other) have pursued knowledge that is participatory, action-oriented and brings about change, they have different positions on the nature of knowledge production.

Utilitarian-motivated action research and community-based participatory research argued that the dominant scientific paradigm (where knowledge is produced by reducing reality to a series of isolated problems) limits our understanding of the relationships between processes. It does not account for the complexity of these relationships and reinforces a partial view of phenomena, particularly excluding knowledge that cannot be immediately quantified. While this approach did not change the basic assumptions of knowledge production, it identified the need for affected communities to be involved in overcoming these problems. For example, communities could contribute by:

- studying subjective factors in health systems effectively;
- measuring determinants and outcomes without high cost technology or skills;
- increasing the capacity and involvement of those directly affected; and
- enhancing the potential for action outcomes from the research findings.

The extent of participation and control of those experiencing the problem varied and the interaction with the researcher was determined by that variation (Loewenson, Laurell and Hogstedt, 1994).

Emancipatory participatory action research generated a different model for producing knowledge. This model recognized that knowledge production reflected and reinforced existing power relations and that conflict over knowledge both reflected and drove social and power relations. In various forms, discussed later, this research approach asserted a principle of 'no delegation' in assessing reality. It used methods to collectively share, analyse and validate experience within social groups directly

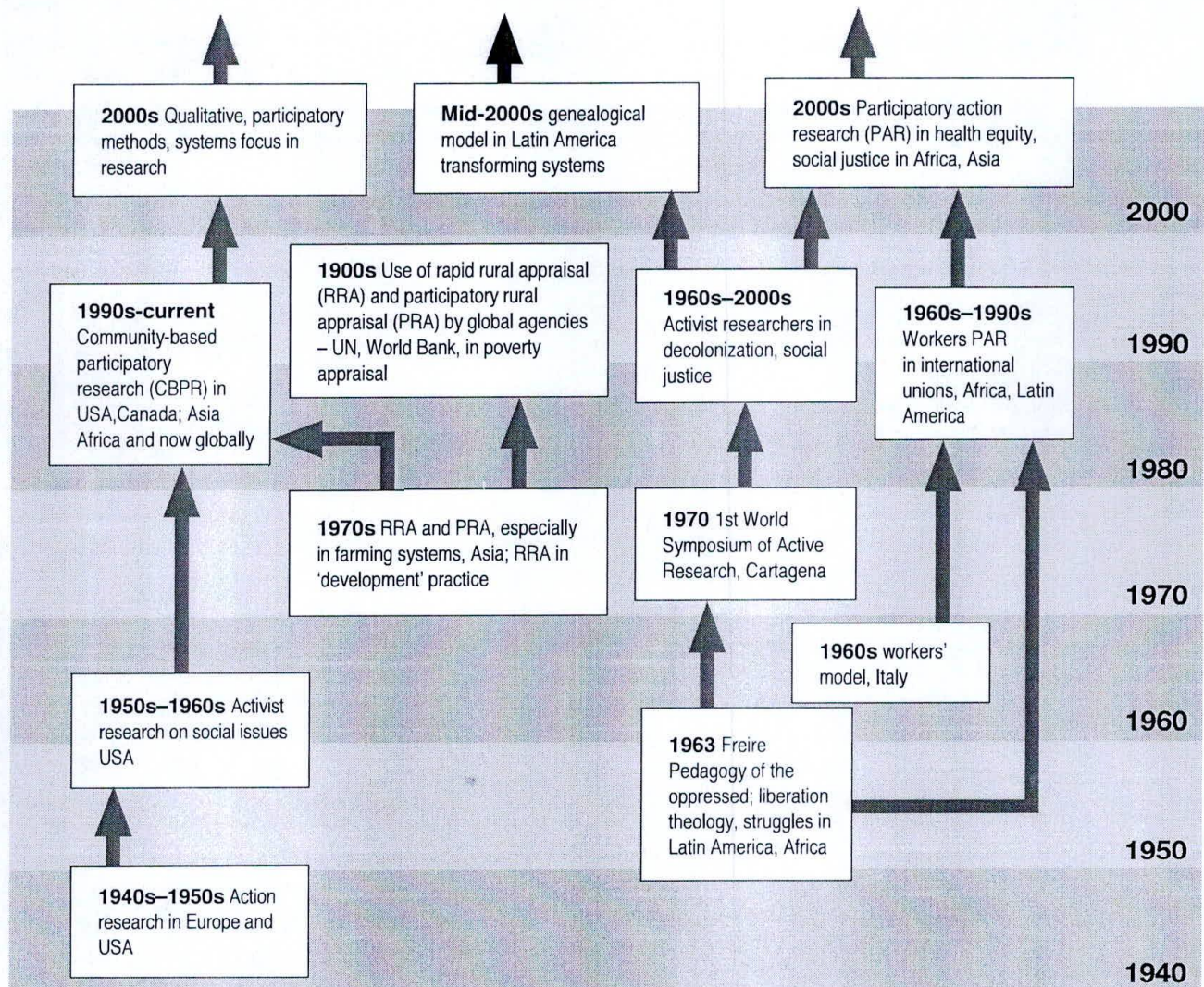
affected by the problems under investigation to build new knowledge. This challenged 'expert knowledge' that had tended to dismiss, marginalize or even suppress the experience of the majority. It evolved into a means of organizing the knowledge of ordinary people, with the researcher as facilitator of this process.

Over time, with widening globalization, the structural factors and social determinants affecting health and access to health care within and across countries have become less geographically circumscribed. So too have the levels of social response to these determinants. The limitations of positivist approaches (*section 1.3*) in understanding the social causes of ill health and social norms, mechanisms and contexts have become clearer,

and have motivated new critical thinking, research methods and tools in health systems (Breilh, 1979; Krieger, 2001; WHO CSDH, 2008; Navarro, 2009; Rifkin, 2009).

This section has described how even within different forms of participatory research, there are inherent tensions over the model of knowledge production, the motivation for the research – whether instrumental or emancipatory – and the researcher–community/practitioner relationship. The rest of *Part one* explores these debates over knowledge and over the relationships in collaborative research further, to better understand these tensions and how they affect the methods and processes used in participatory action research in health policy and systems research.

**Figure 2: A brief historical timeline of major streams and approaches in participatory research**



Source: Authors from text. Note many connections, processes and links exist, the figure only shows the main timelines and features raised in this section as indicative of diverse streams of development of participatory research and key forms of participatory research.

### 1.3 The nature and production of knowledge

The previous section outlined the development of different forms of participatory and action research that have emerged in different socio-political contexts. This section explores how these research methods have also been informed by debates on the nature and production of knowledge.

Guba and Lincoln (1994) identify three areas of questioning on the nature of reality and knowledge, the answers to which help define broad inquiry paradigms:

- Ontological questions – *What is reality? What is the form and nature of reality?*
- Epistemological questions – *What is knowledge? What can be known about reality?*
- Methodological questions – *How can knowledge about reality be produced? How can the person seeking knowledge go about finding out whatever he or she believes can be known?*

#### Positivism and post-positivism

Positivism is a research paradigm that has dominated the natural and social sciences for four centuries. According to this view, a single observable reality exists. Knowledge can be derived from this reality using impartial measurements that are free from contextual or subjective influence (Guba and Lincoln, 1994; Lincoln, Lynham and Guba, 2011). The researcher is pictured as standing behind a one-way mirror, objectively viewing and recording natural phenomena as they occur. According to a positivist worldview, reality is independent of the experience of it (Guba and Lincoln, 1994). The scientific method is the only recognized source of knowledge (Leung, Yen and Minkler, 2004). Knowledge is value-neutral and is produced by the 'disinterested' researcher (Carr and Kemmis, 2003:73).

In recent decades, a post-positivist view has emerged that, while not fundamentally contesting the basic assumptions above, adopts a position that reality, while objective, can only be imperfectly and probabilistically apprehended. This view acknowledges that subjective evidence is necessary to build a more holistic model of reality involving a multiplicity of factors and forces. The inquirer is

still, however, positioned as objective and neutral, seeking to test hypotheses.

Social scientists in particular have increasingly recognized the limitations of positivist and post-positivist paradigms. Scholars have observed that, by virtue of their choices of topics, settings and methods, researchers impose value judgements on research and, by extension, on the knowledge generated from research (Krieger, 1994; Pearce, 1996; Susser and Susser, 1996; Schwartz et al., 1999; Heron and Reason, 1997; Lincoln, Lynham and Guba, 2011). In quantum mechanics, the Heisenberg uncertainty principle and Bohr complementarity principle both assert that the act of observation influences the phenomena being observed.

These observations raise questions about the neutral objectivity that is proposed in positivist inquiry and imply that facts are facts only within some theoretical framework. If different theories might be equally well supported by the same set of 'facts', then knowledge can be viewed as an outcome of the interaction between the inquirer and the observed reality (Lincoln, Lynham and Guba, 2011).

#### Knowledge and subjectivity

This understanding has led to paradigms of inquiry that recognize knowledge as plural, relative and subjective. Paradigms such as critical theory and constructivism, for example, hold that reality is an ever-changing product of social processes and that access to reality occurs through social constructions, such as language and shared meanings (Napolitano and Jones, 2006). According to these views, analysis is neither objective nor knowledge neutral. Here, knowledge is 'subjective, context bound, normative and in an important sense, always political' (Carr and Kemmis, 2003: 73).

By locating the nature and production of knowledge as an outcome of social relations, participatory action research draws on and develops critical theory and constructivism. In participatory action research, knowledge is built out of the collective comparison of subjective experiences of reality by groups of people commonly exposed to, acting on, and/or with first-hand experience of that reality. The extent to which information comes from lived experience (*vivencia*) and action, and is collectively validated, constitutes the measure of reality (Fals Borda, 1987:332: *Part five paper 2*; Loewenson, Laurell and Hogstedt, 1994).

*No delegation* is central to participatory action research. Delegating to another 'expert' and/or to other technical frames of reference risks losing shared lived experience (Misiti et al., 1985). Furthermore, acting on reality itself becomes an important way of building new knowledge. *Praxis* is the process of repeated cycles of action and reflection, that build new knowledge and that move from practical problem solving towards more fundamental social transformation (Fals Borda, 1979; Rahman, 2008).

Different paradigms of inquiry have implications for democratizing knowledge, for the rights of people to increase the stock of knowledge as part of their claims as citizens, and for how knowledge is used to reinforce social interests, power and position (Cammarota and Fine 2006; Breilh, 2011).

### Participatory paradigm

Participatory inquiry emerged as a further paradigm in its own right (Lincoln, Lynham and Guba, 2011). The participatory paradigm asserts that people cannot be mobilized by a consciousness and knowledge other than their own and that 'endogenous consciousness-raising and knowledge generation' is a process that 'acquires the social power to assert vis-à-vis all elite

consciousness and knowledge' (Rahman, 1985: 119). In the genealogical perspective, mentioned earlier, this (self)consciousness is argued to be an ever-changing product of society, and is changed by everyday practices and by the actions taken to transform reality (Faria de Aguiar and Lopes da Rocha, 2007).

Table 1 summarizes these different assumptions and paradigms used in generating knowledge, relating them to the three question areas raised earlier of what is real, what is known and how to generate knowledge.

**Participatory action research** sees that action and reflection must go together. Praxis cannot be divided into a prior stage of reflection and a subsequent stage of action. When action and reflection take place at the same time they become creative and mutually illuminate each other.

Through praxis, critical consciousness develops, leading to further action through which people cease to see their situation as a 'dense, enveloping reality or a blind alley' and instead as 'an historical reality susceptible of transformation'. This transformative power is central to participatory action research (Baum et al., 2006:856).

**Table 1: Characteristics of inquiry paradigms**

	Positivism	Postpositivism	Critical theory	Constructivism	Participatory
<b>Ontology</b> What is real?	A single observable reality exists and can be apprehended	<b>Critical realism:</b> Reality exists but can only be imperfectly and probabilistically apprehended	<b>Historical realism:</b> Reality is shaped by social, political, economic, gender values; and clarified over time	<b>Relativism:</b> Local realities co-constructed by society	<b>Participative reality:</b> Reality is subjective and co-created. It can be apprehended through subjective experience and action
<b>Epistemology</b> What is knowledge? What can be known about reality?	<b>Objectivist:</b> Knowledge of reality is possible through value neutral, impartial observation	<b>Objectivist:</b> As for positivist, but community perceptions needed for holistic understanding	<b>Transactional/subjectivist:</b> Knowledge is subjective, value mediated and context specific	<b>Transactional/subjectivist:</b> Knowledge is socially constructed	<b>Critical subjectivity:</b> Shared experience, participatory analysis and action is used to build socially constructed knowledge and self-awareness of reality as susceptible to transformation
<b>Methodology</b> How can knowledge about reality be produced?	<b>Experimental:</b> By observation and methods for verification of hypotheses	<b>Modified experimental:</b> Methods to test falsification of hypotheses	<b>Dialogic/dialectical:</b> Through inclusion of subjective meanings	<b>Hermeneutical/dialectical:</b> Through shared meaning and social construction	<b>Political participation</b> in collaborative action inquiry; primacy of the practical; grounded in shared experience

Source: Adapted by authors from Heron and Reason (1997); Guba and Lincoln (2005) and Lincoln et al. (2011)

## Popular knowledge systems

Popular knowledge systems reflect these struggles over the purpose, production and use of knowledge. Foucault observes that popular knowledge systems are embedded in and specific to local communities:

*What I would call popular knowledge ... is far from being a general common-sense knowledge, but is on the contrary a particular, local, regional knowledge ... which owes its force only to the harshness with which it is opposed to everything surrounding it – that it is through the reappearance of this knowledge, of these local popular knowledges (sic), these disqualified knowledges, that criticism performs its work (Foucault, 1977: 82).*

Popular knowledge systems have been documented throughout history: in traditional health systems, in knowledge for basic survival and in the collective perceptions of marginalized groups (Tandon, 1981; Fals Borda, 1987: *Part five paper 2*; Cammarota and Fine, 2006). Such popular knowledge has often been disqualified and subjugated, with elite control over knowledge being used as a way of maintaining a dominant status quo against pressures for social transformation (Tandon, 1981):

*...oppressed groups are kept in their disadvantaged social position by turning them into passive recipients of the 'social reality' created by the dominant members of society (Estacio and Marks, 2010: 549: Part five paper 4).*

However, knowledge built from shared experience and action is not always local or marginalized. Subordinate groups accumulate knowledge that at moments in history can have an impact on wider change in society and in systems. As highlighted in the second section of this chapter, social struggles and change have widened recognition and use of popular knowledge. Hence, for example, factory workers have organized knowledge on their experience to raise recognition of occupational diseases (Loewenson, Laurell and Hogstedt, 1994)

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Estacio and Marks (2010) worked with a small indigenous community in the Philippines to generate community-based knowledge to provoke and inform social action. The paper describes the struggle over indigenous knowledge, and the risks for communities in terms of the hostility and aggression they faced in the process.

and social movements of people living with HIV have played a role in exposing evidence and new perspectives on equitable access to medicines (Buse and Hawkes, 2013). This struggle over knowledge and its purpose for action (as practical knowing) and transformation 'in the service of human flourishing' is fundamental to participatory methods (Heron and Reason, 1997:274).

In summary, participatory action research sees the aim of inquiry as not only to explain or predict but also to understand and transform reality. Freire identified that such reflection and action was necessary for emancipation from oppressive social structures (Freire, 1970), while Tandon (1981) identified participatory knowledge as 'the single most important basis of power and control' (Tandon, 1981:23).

While values are discounted in positivist paradigms, they are inherent to participatory action research. The positivist inquirer is an objective observer, interpreting subjective experience as bias and making efforts to create neutral subject-object relations. In participatory action research, the subject of the research is also the inquirer, building knowledge from direct shared experience, engaging in self-reflective action, and seeking knowledge to transform.

## 1.4 Researchers

The positioning of researchers and those involved in the realities studied is, as elaborated in section 1.3 above, at the heart of participatory action research. The methods for this are discussed in Part two. In this section we outline the implications for the 'researcher' in this approach to research.

Researchers and communities are traditionally viewed as having different interests in knowledge production. Communities are positioned as being more interested in solving particular practical problems and academic researchers are positioned as experts with 'scientific knowledge'. This view carries an implicit imbalance in power relations and resources. Academic expertise may silence the community voice and the resources offered may overtly or covertly guide the priorities that communities have for new knowledge.

Researchers report their findings in academic journals. They use technical language, they do not involve the affected communities and thus they retain control over the published knowledge (Leung, Yen and Minkler 2004). When researchers interpret the

reasons for their findings in the discussion sections of their papers, this arguably privileges their own perspectives and limits the external validity of their conclusions (Young and Wharf Higgins, 2010). This view of only a neutral, objective researcher being able to apprehend reality is contested, as noted earlier. Researchers themselves are seen as having theories and values that affect their interpretation of facts, as demonstrated, for example, in *Box 1* below.

### Relations with communities

The spectrum of relations between researchers and communities is described in Table 2 on page 24.

In action research and some forms of community-based participatory research, the relations are collaborative, with input and action from communities. However, the process is still organized (and controlled) by the

researcher. In this situation, the research relationship is based on mutual interest and partnership in the process (Mergler, 1987). For the researcher, collaboration is a necessary part of knowledge accumulation. In action research, only by embedding the investigator in the context under study can knowledge with tangible practical consequences be accumulated (Denis and Lomas, 2003). While the distinction between the scientist and the non-scientist is preserved, there is a mutual respect for the distinctive expertise that each brings to the research process. The researcher may involve communities in defining the agenda, in reviewing tools, evidence and reports, but often maintains control over interpreting and analysing the findings.

The relationships differ in emancipatory forms of participatory action research and in some forms



#### Box 1: How ideology biases receptivity to research

Psychologists have elegantly demonstrated how our subjective values bias our reaction to research findings.

Lord, Ross and Lepper (1979) did a survey of a class of undergraduates to evaluate the strength of their opposition to or support for capital punishment. The two groups of undergraduates that had the strongest support and opposition were used as the sample.

Results of research on capital punishment were presented to the students. Half of each group heard research that supported their preconceived ideology, while half heard research contradicting their preconceived ideology. The researchers then assessed what impact this had on the students' attitudes to capital punishment.

After this they presented the methods used to arrive at the results to the students. They again assessed the students' strength of support for or opposition to capital punishment.

Perhaps predictably, when confronted with results in support of their initial ideology, the students embraced the results and the research was used to strengthen their preconceived views. Subsequent presentation of each study's methods had limited additional impact.

In contrast students presented with results contrary to their ideology changed their views only minimally or not at all in the direction of the findings. Criticism of the methods was used as the 'excuse' to reject research contrary to their initial ideology.

In a twist of study design the experimenters had controlled for the quality of each study. They had reconstructed each research report so that half the time it had the original methods but half the time they inserted the methods used in an opposing study.

Students were indiscriminate in their use of methods to reject 'uncomfortable' research findings. Methods used in studies recently embraced for their confirmatory value, were now used to reject contrary findings.

As Marmot (1986) has pointed out:

*When facts collide with theories, scientists are far more likely to discard or explain away the facts than the theory.*

Source: Lord, Ross and Lepper (1979)

**Table 2: The participation continuum**

Role	Compliant participation	Directed consultation	Mutual consultation	Co-investigation	Emancipatory PAR
Professional researchers	Provide community with balanced information about the research aims and process. Recruit subjects according to the project's design. Researchers are in complete control of the research	Consult with community members on research-identified tasks to take advantage of the community members' unique perspectives. Input limited to specific tasks. Researchers retain complete control over study	Develop a long-term partnership with community members that offers a holistic understanding of the project and its goals. Input no longer restricted to specific topics, concerns or tasks. Researchers retain control over study	Develop egalitarian partnerships with community members that equalize the decision making power between researchers and community members. Work collaboratively to make research decisions including the goals, scope, design and use of the research	People from outside the community are involved in participatory action research as facilitators, and have commitment and competencies to facilitate social dialogue. May also act as secondary voices to illuminate theory developed by community members
Community members	Voluntarily consent to participate as 'subjects'	Provide advice on researcher-identified questions or tasks based on their own knowledge and experiences	Develop a longer term relationship in which community members engage in sustained communication with researchers about the project. Project is understood holistically, thus community input may directly shape any aspect of the study, including its purpose and applications	Develop egalitarian partnerships with community members that equalize the decision making power between researchers and community members. Remain engaged in research and take responsibility for making collaborative decisions about the research	Principle of no delegation implies that community members are the researchers. The research takes into account which social groups are involved, with what shared experience, interests and possibilities to act as a group

Source: Adapted by the authors from Chung and Lounsbury (2006)

of community-based participatory research that shift control over knowledge production more fundamentally to communities. The principle of no delegation in inquiry, discussed further in *Part two*, means that the communities involved are themselves researchers through their own collective inquiry. In this situation, researchers from outside the community with shared values can play a facilitating role in the process. Such researchers need to have an explicit understanding of the power dynamics in the conflict over knowledge and their own position in it. This analysis of society and social power is further discussed in the next section, particularly in relation to health systems.

The researcher's role is to facilitate the organized processes and methods that enable those directly involved to collectively share, analyse and validate their experience. This means that reflection, interpretation and knowledge are generated and held within the community in the process (Loewenson, Laurell and Hogstedt, 1994). Participants take

equal ownership of the research question and process, making the research outcomes accessible, understandable and relevant to their specific interests and needs (Leung, Yen and Minkler, 2004).

### Competencies and challenges

Participation demands time, an enabling context and communication skills for the necessary mutual understanding and trust to develop between researchers and communities. Researchers from outside the community may face a challenge in engaging with power relations and ceding initiative to the community (Denis and Lomas, 2003). Nathan, Stephenson and Braithwaite (2014) observed in work in Australia that even within communities engaged in participatory work there are struggles for legitimacy and change. Communities may never gain control over the process or may lose this control while activist researchers may direct communities towards their own ideology (Oslender, 2013).

Researchers in participatory action research thus need to be accountable for their role and for the ethical practices demanded by the unique nature of this approach (discussed in *section 3.1*). If a rights framework is used, researchers are community members who are themselves rights holders but equally they are duty bearers who must ensure ethical practice and the shift in control. *Box 2* shows examples of tools used to raise awareness of the power relations in research and to demonstrate how to engage with them.

At the same time, the process of transferring power and control from researchers to participants can be challenging. Social groups that have been oppressed and marginalized can struggle with issues of low self-confidence and learned helplessness. This can impact on their motivation to participate in the research, particularly for those most marginalized and most in need (Rosenthal, 2010; Othieno et al., 2009: *Part five paper 5*). This feeds into the proximity paradox discussed in *Part three*, where the most vulnerable groups are least accessible for and involved in processes that generate new knowledge (Ritchie et al., 2013).

In addition to the usual skills in reviewing the field, and managing and organizing research, facilitators and researchers using this approach need strong interpersonal and social competencies, including:

- An ability to adopt a relational stance of mutual respect;
- Respect for (and ability to draw on) different forms of knowledge, capability and resources;

- A commitment to understanding social realities;
- Sensitivity to diverse value systems and affirmation of the culture of the community;
- Ability to reflect critically on the research experience;
- Capacity to contribute to group reflection;
- An ability to engage in frequent, honest and productive dialogue;
- Skills in listening to and reporting information;
- An ability to use interpersonal and communication skills for the benefit of others; and
- Integrity and trustworthiness, emotional intelligence and humility (Loewenson et al., 2006).

Researchers involved in participatory action research also face challenges. These include:

- Understanding and managing cultural diversity and mistrust, power dynamics, the collective memory of oppression and other social patterns that influence, sometimes negatively, the social participation and collective interaction in this research;
- Accepting communities' refusal to participate that may in the short run lead to failure and frustration (Oslender, 2013);
- Engaging with social experiences and realities within communities different from those in their own lives (for facilitators from outside the community) even if they share values;



## Box 2: Tools for engaging with power relations in research

Various resources have been developed to help researchers understand and engage with the power relations in research.

The 'white privilege' checklist developed by Peggy McIntosh (<http://crc-global.org/wp-content/uploads/2012/06/white-privilege.pdf>) supports members of the dominant culture or value system in better understanding the unspoken advantages they carry by virtue of their race and how these advantages can affect their work with other cultures. This exercise can be used to facilitate a discussion of what unearned privilege means and how that may affect working relationships with diverse cultures.

The Community Tool Box (<http://ctb.ku.edu/en/tablecontents/chapter1027.html>) includes resources for building relationships with people from different cultures; learning to be an ally of people from diverse groups and backgrounds; and strategies and activities for reducing racial prejudice and racism.

Source: Minkler, Rubin and Wallerstein (2012)

- Working with indigenous knowledge processes that are often local and oral;
- Facilitating processes that bring together groups with different experiences to build shared knowledge and action, in ways that do not subjugate one group's experience over another;
- Handling conflict and sometimes threats or violence within social processes, understanding its sources and how to manage it; and
- Managing different and sometimes competing agendas (Baum et al., 2006; Kwiatkowski, 2011).

Researchers themselves need support in managing these challenges, for example, from the learning networks described in *section 4.3*. As the desired changes are located in social processes, they may take a long time to achieve. People from outside the community may not be able to sustain their links with communities for long enough to facilitate, support or document such changes. On the other hand, communities may not see the need to document the changes achieved, weakening the sharing of the outcomes phase of this process. These challenges are further discussed in *section 2.5* on evaluating action,

in *section 2.7* on institutionalizing this approach and in *section 4.1* on reporting.

For academics the research process may be time-consuming, unpredictable and unlikely to lead to many published articles in refereed journals. The somewhat unpredictable outcomes of this research approach can also make it a challenge for competitive research funding.

As discussed in the next section, tackling conflict and transforming power relations is an inherent part of the process. The methods themselves assist in overcoming some of the challenges raised above. *Box 3* describes, for example, how researchers and social organizations built relationships of trust even within the limited political space at the time of the Chilean dictatorship.

Other actions can be taken to address the challenges researchers face. The relationships of trust needed in this approach are considered more likely to thrive when there is both structured and unstructured interaction between those inside the community and those working with them from outside (Denis and Lomas, 2003; Bourke, 2009). While acknowledging the power imbalances and issues within communities, people from within the community have reportedly been able to facilitate research themselves, thus



### Box 3: Mutual strengthening of researchers and social organizations under repression

Falabella (2002) discusses the relationship between research groups and civil organizations in the context of the Chilean dictatorship. The researchers facilitating the participatory action research recognized the value of sophisticated preparation, strong socio-political commitment and competencies in facilitating social organization and dialogue. The process was seen as providing space for independent thought despite the strong repression. Civil organizations valued the professional scientific support in advancing their interests, systematizing experiences, building self-esteem and providing the space particularly for women to affirm their identity and values and participate in socio-political action.

Despite a context of neoliberal promotion of self over class and society, this process provided space to redefine the nature of social movements and organizations. The relationship between social groups and researchers was described as 'non-corporate', respecting and developing the autonomous capacity of each entity, 'so that they do not dissolve in the relationship' but both are enriched by it.

In contrast, the perspectives of participatory action research are less promising in Chile today. The Chilean democratic transition has preserved neoliberal values and weakened civil organizations, with political parties claiming they represent the citizens. Academic requirements for individual publications and financing are also affecting the uptake by academics or the reporting of participatory action research projects.

Source: Falabella (2002)



#### Box 4: Community health workers as researchers

Conducting research in a way that is respectful of the community and its residents' norms, values and traditions while maintaining the rigour necessary for academia can be difficult. In work carried out along the Texas–Mexico border, a community–academic project was set up where university-based researchers developed a partnership with *promotoras de salud* (community health workers, hereafter referred to as '*promotoras*') as research collaborators to address this issue.

Involving a team of *promotora*–researchers in a project focusing on food and diets in the community made a significant contribution to the quality of the research. *Promotora*–researchers were fully involved throughout the project life cycle, from conceptualizing it initially, including pre-planning, pilot testing and collecting data through to interpreting and disseminating research findings at scientific and *promotora* conferences and workshops.

*Promotora*–researchers were able to support and encourage the participant–mothers and help them recognize their own value in ways that drew a richness of evidence that may not otherwise have emerged. These researchers were skilled in facilitating research due to their role as cultural brokers (navigating the community, the health system and, to an extent, academic environments) and their status as co-residents and community-recognized leaders in health promotion and advocacy:

*Without the promotora–researchers' ability to support and encourage the participant–mothers throughout data collection, it is unlikely that the project would have had enough quality data for analysis. This research also benefited from the promotora–researchers' self-initiated actions to 'win over' participant–mothers, and help them recognize their own value. Resulting interviews produced rich data that captured the meaning behind mothers' food choices.*

Source: Johnson et al. (2013: 639)

increasing the possibilities for valid knowledge that results in social action. An example of this is described in Box 4 above and also by Peacock et al. (2011) in work with community health workers in Chicago (section 2.3, Box 16).

For academic settings, Gibbon (2002) notes that using participatory action research in doctoral research in health involves managing conflicts of interests and ensuring integrity of methods, timing and the type of information generated. He calls for academic institutions to consider how to minimize such obstacles. As discussed later, reflexive and participatory processes are gradually being understood, valued and accepted as legitimate research methods in health by public health journals, funding bodies and universities, reducing these barriers, but progress has been slow. The challenges to and options for strengthening publication of participatory action research are further discussed in Part four. Academic researchers also receive little training in how to facilitate participatory approaches (Ponic et al., 2010). Researchers in academic settings are thus more often encouraged by the shared values, activism, new and unique learning opportunities and

social transformation (and enjoyment) that can come from these processes. The success of participatory research is argued to depend as much or more on the people involved as on the processes they put in place (Denis and Lomas, 2003). This reader provides further support to such people.

### 1.5 Power and participation in health systems

Previous sections explore the features and history of participatory action research, the concept of knowledge it uses, and the implications for researchers. Across all is the central role of those usually participating as the subjects of research as active researchers and agents of change. Participatory action research shifts power towards communities involved in generating knowledge, acting on it and gaining greater control over the conditions and services that affect their lives. These researchers engage with and need to understand issues of power and participation in health systems. This section discusses this further.

As noted in *section 1.1*, health systems are themselves complex social systems that reflect, affect and build social values. They encompass diverse public and private actors and agents – with conflicting needs, values and interests – that play a role in implementing the functions and elements shown in *Box 5* below and described in further detail in other sources (Gilson, 2012).

In all this activity, power and participation play a role (WHO CSDH, 2008), including in the interactions and interrelationships between the elements of the system and the network of public, private for profit and not for profit organizations and civil society institutions, resources and actors that make up the system and that influence outcomes (Matheson, Howden-Chapman and Dew, 2005; Loewenson, 2010). As noted in *section 1.1*, the persistence of disparities in health and access to health care based on race, ethnicity and social class, and the inverse care law in the availability, access to and uptake

of health services in low, middle and high income countries, underscores the need for an improved understanding of these social dimensions of health systems, if these systems are to improve population health (Tandon et al., 2007; WHO CSDH, 2008; Rifkin, 2009).

Participation is commonly referred to in health systems. It reflects the value and role of active citizenship and was a founding principle of primary health care in the 1970s and of renewed calls for primary health care from WHO in the 2000s (Rifkin, 2009). If people have been involved in decisions about how health services are delivered they are more likely to trust, use and respond positively to them as well as to take action or contribute to health, as exemplified in *Box 6*.

While social participation is a recognized goal in health systems, it holds different meanings in the way it is implemented. Arnstein (1969) described



## Box 5: Functions of health systems

Health systems can be understood as:

- 1 Encompassing the population the system serves, including:
  - patients with health needs requiring care;
  - clients with expectations of how they will be treated;
  - taxpayers who provide the main source of financing for the system;
  - citizens who may have access to health care as a right;
  - co-producers of health through their health-seeking and health-promoting behaviours.
- 2 A set of functions or building blocks:
  - health workforce;
  - service delivery;
  - information;
  - medical products;
  - technologies and vaccines;
  - various dimensions of financing, public and private;
  - leadership/governance and regulation.
- 3 Incorporating, within the service delivery functions:
  - general curative and preventive health services and those aimed at specific health problems;
  - a range of modes or channels of service delivery including various levels of facilities, other outlets for health goods (such as pharmacies or shops) and other strategies (such as community-based health workers and activities);
  - a complex mixture of service providers – public and private, for profit and not for profit, formal and informal, professional or non-professional, allopathic or traditional, remunerated and voluntary – the pluralistic health care system

Source: Gilson (2012)

the eight rungs of the 'ladder of community participation' (manipulation, therapy, informing, consultation, placation, partnership, delegated power and citizen control). All these levels are practised within health systems. A significant body of critical literature on the nature of participation in health systems clarifies that participation without redistribution of power, while often practised, is a hollow and ritualistic process. Arnstein (1969) describes participation where people are 'educated' and consulted as 'therapy', giving the impression of a meaningful role, but where participation is a form of rubber-stamping or even manipulation. Power is rather redistributed by claim, negotiation or struggle, and this itself demands an organized and accountable power base within the community (Arnstein, 1969).

Health is understood as a *social* right, a common good and state duty directing attention away from token forms of participation and towards approaches where public actors and communities play a key role in co-determining, resourcing, implementing and reviewing services and in co-producing health outcomes. Participation is understood as a feature of active citizenship, not only for the most articulate or well positioned in the community but for all social groups, and through approaches that involve people collectively. This debate on participation as token versus participation as meaningful shifts in power is important in also understanding the power shifts essential in implementing participatory action research. It draws the connection between this kind of research and other socio-political processes.

## SEE PART 5: PAPER 10

Maalim (2006) shows how current service planning processes have marginalized Somali nomadic communities. When members of this community drew a descriptive diagram of their seasonal movements in a study they identified both this nomadic community's perception of health care services and how they could be improved to suit their nomadic lifestyle. Maalim postulates that these approaches would be more effective than current tools for planning services for the community, as they engage better with the intricate information network of this community.

Hence for example social movements have played a crucial role in participatory action research and given it impulse (Vega-Romero and Torres-Tovar, 2011).

However the role of the market and economic agents in health introduces different interests and understanding. Commercialized services position people as consumers of health commodities and services with (or without) purchasing power, rather than as citizens with rights to services. A retreating state can leave those excluded from the market, especially women, to take on inappropriate burdens of care. Participation thus emerges as a function of a retreating state, with citizens taking on roles of consumers and self-providers (Laurell and Herrera Ronquillo, 2010; Waitzkin, 2011; Cornwall and Coelho, 2007). How health systems organize participation can thus have a strong effect on the social roles and relations being built within the health system and in interaction with wider society.



### Box 6: Benefits from participation for Cape Town's health system

The Cape Town Equity Gauge encouraged programme managers to participate in research on the socioeconomic determinants of health across the sub-district health structures of Cape Town. The Gauge produced an equity measurement tool to quantify inequity in health service provision in financial terms and an equity resource allocation tool to advocate for and guide action to rectify inequity in this provision.

The work used the three pillars of (a) assessment and monitoring, (b) advocacy and (c) community empowerment to increase social participation and support for managers through shared analysis of health outcomes. The authors attribute changes in practice to stakeholders being involved and empowered. Changes were achieved, for example, by giving health managers the tools to gather evidence and challenge colleagues in sectors such as housing and sanitation. They were able to better engage with their political bosses on the socioeconomic and service delivery inequities that affect people's health in Cape Town.

Source: Scott et al. (2008)

Health systems are themselves located in and interact with societies that are complex networks of interrelations. These interactions involve institutions, communities, social groups and classes, frequently with divergent interests and contradictions among them. The basic characteristics of society have been blurred by the idea of individuals all having equal opportunities, despite contradictory evidence of growing inequality. Society is instead a complex fabric. Its structure is shaped by historical processes that we have to consider if we want to understand and transform society. Social classes and the relations between them define how wealth and power are distributed.

In the prevailing neoclassic economic doctrine, economic relations dominate and the market is used as the organizing principle of society (Stiglitz, 2002). Social classes are not only affected by new forms of labour relations but also by processes like colonization and by gender, migrant, cultural and political relations. The distribution of knowledge in society also influences the structure of society (Wallerstein, 2005; Obando-Salazar, 2006; Zavala, 2013). Diversity and inequality in these different spheres affect the distribution of power, the representation of interests and the possibilities for effective social participation.

The power relations that derive from these interactions affect the control that people have over events and resources. For example, they affect whether one group exerts power 'over' another and whether groups can claim the power to be part of processes. Power relations influence whether groups exert a shared power 'with' each other or build a shared consciousness of themselves and their conditions in the form of a power 'within'. These power relations are not static and can be changed for example by organizing and acting or by creating new and/or different knowledge (Korpi, 2007; Ponc et al., 2010). Power can thus constrain societal action but it may also enable action for change and transformation.

Participation without this redistribution of power is identified as a frustrating process for the powerless (Kwiatkowski, 2011). It is exemplified by processes

that influence individuals and populations to actively self-regulate their own behaviour in alignment with dominant power. These are top-down approaches that engage communities through interventions defined, managed and evaluated by health professionals and through privileging biomedical knowledge over communities' own understanding of the causes of their ill health (Foucault, 1977; Rifkin, 2009). Participation as used in participatory action research approaches is understood as a way of redistributing power and building shared power. As outlined in the definition by Wallerstein (1992) in *Part one*, empowerment can be understood as a conscious activity undertaken by a social group for a positive change in their lives.

This reader, the papers cited in it and those presented in *Part five* highlight the various ways participatory action research is being used in health policy and systems research in low, middle and high income countries and in different health system settings and on diverse issues. Participatory processes that generate knowledge and a shift in power are described in the following processes where community groups:

- demand more and better services (Borgia et al., 2012, *Part five: paper 17*);
- claim a role in planning and operating services (Murthy and Klugman, 2004 and Mbwili-Muleya et al., 2008, *Part five: paper 6*); and
- participate in decision-making or in the alliances built on access to medicines (Loyola, 2008, Batista et al., 2010, *Part five: paper 15*).

The notion of participation does not imply giving any less attention to evidence in decision-making. It rather widens the range of evidence being used in decision-making and the range of actors judging and interpreting that evidence (Kwiatkowski, 2011).

Participation in providing accurate and relevant information is argued as essential to improve health outcomes in primary care, to improve patient-provider relations and to promote shared decision-making in personal care services by taking the patient's perspective into account. It is argued that chronic care benefits greatly from information on patients' views, for example, in improving uptake of care in diverse groups, and in developing patient-centred care systems, both of which are important for managing long-term illness (Bélanger et al., 2012).

#### SEE PART 5: PAPER 4

Estacio and Marks (2010) provide evidence of the alienation and exclusion that occurs when people's own knowledge systems are not integrated within health systems.

Participatory action research can be an effective way of organizing community evidence and perceptions to improve health system functioning, especially when findings are triangulated with evidence from other sources. It has facilitated understanding and resolved problems in roles and relationships within health systems. By clarifying the social determinants of health, this approach adds evidence to improve the performance and effectiveness of health systems, as in the example of cardiovascular health in *Box 7* below. The methods provide a means of recognizing and detecting health problems in good time, including those that were previously hidden – for example, chronic diseases, work-related health problems among health workers and those related to the social determinants of health (Minkler, 2000; Waterman et al., 2001; Loewenson et al., 2011; Hatton and Fisher, 2011).

Conflict is a basic characteristic of society and participatory action research recognizes this. Even where a broader political space exists and power relations are more consensual, these are seen as the result of prior resolution of conflict. The emancipatory forms of participatory action research described earlier pay attention to how the processes for generating knowledge link to people gaining control over their lives and overcoming structural exclusion, such as through grass-roots workers' committees and citizens' organizations.

The processes that generate knowledge also increase the collective power to lever transformations towards people-centred health systems. In mental health research, for instance, this approach has been used to respond to demands for a voice in planning

and running services and to stimulate choices and alternative forms of treatment (Otieno et al., 2009, *Part five: paper 5*). It is increasingly recognized as useful in indigenous health research as it has the potential to reduce the negative – and some would argue colonizing – effects that much conventional research has had on indigenous people (Baum et al., 2006).

These approaches can enhance communication within health systems and among health personnel, communities and others. They can foster mutual respect for their respective experience and roles (Mbwili-Muleya et al., 2008, *Part five: paper 6*). The methods in participatory action research encourage primary care health workers and communities to share analysis and power, to the benefit of both. The process builds cycles of learning, reflection and action, and stimulates communities and local levels of health systems to develop and implement locally determined plans. The approach has elicited community values, identified community assets for health and built understanding of the contribution of community voice and agency in addressing the social and systemic barriers to health care coverage, particularly in vulnerable communities (Loewenson et al., 2011).

#### SEE PART 5: PAPER 5

Othieno et al. (2009) give an example of participatory action research being used to transform power relations between highly disempowered people with harmful use of alcohol or mental health problems and their services, to engage on the changes needed to improve service provision and to strengthen collective actions for community mental health.



### Box 7: Using participatory research in cardiovascular health

Cardiovascular health research has been dominated by medical paradigms that minimize the broader perspective of causes of disease. Socioeconomic status as a risk factor for cardiovascular disease is well established from research, yet these findings have had little influence on policy.

Participatory research brought contextualized clinically relevant findings into programme planning and policy-making arenas. This research contributed to developing meaningful health and social policies relevant to primary prevention. The programme opened spaces in practice and policy-making arenas to raise upstream issues relevant to the health of low-income single mothers, yielding evidence that was missed in quantitative databases. The research found that women's elevated risk for cardiovascular disease is located in a cultural ideology where parenthood, most often the work of women, is less valued when one is without a partner and coping strategies include risky behaviours such as smoking as a response.

Source: Young and Wharf Higgins (2010)

At a challenging time for many health systems, Fine (2006) argues that participatory action research has been a means of raising critical questions and engaging with social critique:

*It is a propitious time for participatory work to prick the anesthesia that is settling into our collective bodies. PAR projects gather social critique and outrage, ambivalence and desire, as forms of knowledge. Inquiry is valued as oxygen for democratic sustenance ... With innovation and a proud legacy of activist social researchers, participatory research collectives can interrupt the drip feed, engage critical questions, produce new knowledge, provoke expanded audiences, and allow us to ask as scholars, in the language of the poet Marge Piercy (1982), how can we 'be of use'?(Fine in Cammarota and Fine, 2006).*

Part two describes in more detail the process and methods participatory action research uses to address the features inherent to conceptualizing knowledge and understanding how it is generated and to understanding health systems and the societies they are based on.

## 1.6 Working with other research approaches

In this final section of Part one we discuss how participatory action research relates to, complements or triangulates with other areas of health policy and systems research.

Health policy and systems research addresses questions that are not disease-specific but have repercussions on the performance of the health system. This runs across the elements or building blocks of health systems, as described in Box 5. Health policy and systems research draws on a variety of disciplines. It is predominantly an applied field that starts with a problem or topic arising from practical experience and selects methods to address this problem in the most appropriate manner (Bennett et al., 2010).

Health policy and systems research, as defined in section 1.1, focuses on health policies and health systems – what they are, how they are conceptualized, planned and implemented (policies), how they work (systems) and what can be done to improve their implementation or functioning.

As further elaborated in Gilson (2012), the field :

- is multi-disciplinary, distinguished by the issues and questions addressed through the research rather than by a particular disciplinary base or set of methods;
- includes research focusing on health services as well as on promoting health;
- concerns issues at global, international, national and sub-national level;
- encompasses research on how policies are developed and implemented and the influence that policy actors have over policy outcomes in health systems; and
- promotes work that explicitly seeks to influence policy.

Within the key domains and elements shown in Box 5 in the previous section, health policy and systems research includes a range of types of study that may be exploratory, descriptive or explanatory. They are informed by various disciplinary perspectives:

- *Cross-sectional studies* observe the programme, policy or problem of interest at a particular moment in time. They use quantitative and/or qualitative methods. It is a generic category and some methods identified below are also cross-sectional.
- *Case studies* provide details of particular events, programmes, processes, situations or policies, to understand 'how and why' questions. Analysis across case studies can identify generalizable factors to explain variations. Case studies can be at the micro (individual/household) level, meso (facility/district) level or macro (national and international/ global) level.
- *Ethnographic studies* use ethnographic approaches and methods drawn largely from sociology and anthropology for in-depth descriptions of everyday life and practices in health or health systems, from micro levels (such as interaction between health workers and clients) to macro levels (such as in health policy debates).
- *Impact evaluation* includes experimental and quasi-experimental methods that try to determine the magnitude and strength of causal relationships between the intervention and an outcome, often applying epidemiology and health economics. It tries to establish what would have happened in the absence of the intervention (the counterfactual). Randomized controlled

trials are examples of experimental designs, while difference in difference approaches, matching techniques and regression discontinuity approaches are examples of quasi-experimental methods.

- *Policy analysis and historical analysis studies* examine the evolution of policies, institutions and programmes over time at regional, national and global levels.
- *Cross country analysis* compares multiple country level case studies to identify generalizable factors affecting variations in health systems and the associated national processes and policies, using policy analysis techniques. It includes comparative assessments of health systems performance using standardized/comparable data and health economics and epidemiology techniques to compare and assess performance (Gilson, 2012).

Participatory action research, as described earlier, differs fundamentally from other approaches to health policy and systems research in changing the subject-object relationship and thus changing the power relationships over the process of producing and using knowledge. Further, by embedding learning from action it includes transforming reality as a source of new knowledge.

Summarizing the conceptualizations of knowledge discussed earlier, the differences between the assumptions of the various methods listed and those of participatory action research in health policy and systems research are shown in Table 3 below.

In many forms of health policy and systems research, the assumption is that others – specifically policy makers and public health advocates – are responsible for incorporating the findings of research into health programmes, systems and policies and feeding information back to communities. In participatory action research the social groups directly involved in these issues, including local health and other workers, work with researchers or facilitators, learning from their actions towards changing systems, practices and policies, as part of the process.

Participatory action research approaches may also be used in case studies, policy research, for ethnographic or social and systems analysis or for impact evaluation.

Table 4 on page 35 shows the implications of applying participatory action research approaches in these forms of health policy and systems research. These approaches may be usefully applied to address the goals of certain forms of health policy and systems research, although it would require changes in the process and design, as discussed in *Part two*.

**Table 3: Features of participatory action research versus other approaches in health policy and systems research**

Experimental, quasi-experimental studies and policy, ethnographic studies based on external observation and validation	Participatory action research
Experimental studies are largely based on objectivity and emphasize the value-free nature of the research. Studies based on critical theory and constructivism recognize the role of subjective evidence	A process of knowing and acting – knowledge for its own sake is less relevant than knowledge for change; knowledge is not independent of social relations and may be part of the system of ensuring that one social group (and their understanding of reality) dominates over another; those who generate or reproduce knowledge are thus not neutral in these social relations
Separation between subject and object	Those affected by the problem are centrally involved and it uses collective or co-operative forms of inquiry and analysis. The experience of those affected is the primary source of information for the research
The gap between reality and the researchers' assessment of reality can be closed by refining research techniques	The gap between reality and its assessment can be closed by 'no delegation' – those closest to the experience of reality provide the assessment – and by the collective validation in a group of people who share the same experience
Statistical analysis, triangulation or other methods of external validation provide the only scientific basis for verification	Verification arises from consensual validation (discussed further in Part two) and from evaluating action based on the information generated
The researcher as a skilled, neutral observer	The researcher as a part of the affected community, as facilitator of the affected community or under the control of the affected community

Source: Tandon (1981) and Couto (1987)

The interaction between participatory action research and other health policy and systems research may be sequential, with participatory action research triggering other forms of research. The study of and responses to respiratory problems in North Carolina, USA, described in *Box 8* below exemplifies this. Participatory action research may also be embedded in ethnographic or other studies.

An interaction between participatory action research and other methodologies may be strongly supported by communities. This may be to provide quantitative documentation or to explore and validate findings from participatory action research in those policy or political contexts where this is needed (Leung, Yen and Minkler, 2004). As exemplified in the studies and examples in this reader, participatory action research in health policy and systems research has contributed to knowledge and practice on various dimensions of health systems, either on its own or, in some fields, combined with other approaches (further discussed in *sections 2.7 and 4.2*).

Journals that have more commonly published participatory action research and other participatory approaches in health policy and systems research are those that address health promotion research. They present research on population-based public health approaches to understanding and addressing the social determinants of health and on the organization and practices of health systems. Participatory approaches in health policy and systems research

have also influenced policy and practice in environmental health and in managing market risks, such as controlling smoking and youths' access to alcohol, preventing violence, ensuring continuity of care and occupational health, and reintegrating harmful substances users and people suffering from mental health disorders. The research has been used to support changes that have occurred at neighbourhood, city and state levels (Tandon et al., 2007) (discussed in *sections 2.7 and 4.2*).

Health policy and systems research is making an important leap in highlighting the knowledge about systems, social relations and processes that is needed to address problems that arise in practice. Participatory action research makes a further leap in systematizing knowledge based on the experience of those involved and generating learning from action.

As a research method embedded within social contexts and change, participatory action research is well positioned to take advantage of increasing social capacities, networks, communication and information technologies within society at large. This comes at a time when an informed, health-literate society is considered important in improving performance in health systems. This is thus a key area in health policy and systems research (further discussed in *Part two*) but we can safely say that both health policy and systems research generally and participatory action research in this field are dynamic and evolving fields.



### Box 8: Applying participatory approaches in popular epidemiology

Popular epidemiology uses lay knowledge and observations to challenge social structure factors and uses political and other means to seek solutions. In Tillery, North Carolina, a low-income, African-American community was suffering from high rates of respiratory and related problems. They suspected this was related to the proliferation of hog production, with its open cesspools and lagoons that fouled the air and seeped waste water into their wells and yards.

Community members mapped the location of the hog facilities, determined the depth and construction dates of local wells and used the data to advocate for change. Their popular or 'barefoot' epidemiology laid the groundwork for a successful long-term collaboration with an epidemiology faculty member at the University of North Carolina's School of Public Health and the local health department. This partnership culminated in a major and multi-pronged USA government-supported project that validated the community's initial findings and concerns with carefully co-designed surveys. It also demonstrated a persistent pattern of racial discrimination in the placement of hog industry plants. The research in turn was used by the community and its academic and professional partners to help bring about ordinances and other actions to help curb these unhealthy practices.

Source: Leung, Yen and Minkler (2004)

**Table 4: Applying participatory action research versus other approaches in health policy and systems research**

Form of health policy and systems research	Implications of applying the participatory action research approach In addition to the change in subject-object relationship and processes for direct knowledge generation by those affected
Cross-sectional studies – observe programme, policy or problem of interest at a particular moment in time (may include some of the HPSR forms below)	<p>Participatory action research differs in...</p> <ul style="list-style-type: none"> <li>not focusing on describing a particular point in time but following a cycle of reflection from experience to determine, analyse and act, and build knowledge from action; and</li> <li>not basing findings exclusively on researcher observation but collective observation and validation.</li> </ul>
Case studies – provide detailed descriptions of particular events, programmes, processes, situations or policies, to understand 'how and why' questions.	<p>Shares the desire to explore how and why questions but applies this differently in that this means ...</p> <ul style="list-style-type: none"> <li>moving from describing to search for causes, with direct reflection on problems by those affected and testing the understanding built to learn from action.</li> </ul> <p>The experience of and learning may be documented as a form of case study. It faces similar challenges as case study approaches in generalizing across contexts and settings (discussed further in <i>Part three section 4</i>).</p>
Ethnographic studies – provide in-depth descriptions of everyday life and practices in health / health systems	<p>Shares focus on lived reality and local practice and the primacy of direct evidence from experience of those involved but applying this approach differs in...</p> <ul style="list-style-type: none"> <li>not using expert observation and validation for this but methods for collective organization and validation by those directly involved; and</li> <li>using the action on and transformation of reality to build knowledge.</li> </ul> <p>Some argue this approach provides a more valid form of ethnographic analysis as it systematizes knowledge from those directly involved without the bias introduced by an observer.</p>
Impact evaluation studies – seek to determine the magnitude and strength of causal relationships between the intervention and an outcome	<p>Participatory action research does not assign groups on a random basis and so is not useful in traditional forms of impact evaluation. However it shares concern for understanding the impact of action on reality / systems or the theory of change as used in realistic evaluation. Applying it means ...</p> <ul style="list-style-type: none"> <li>no experimental assigning of groups – the group are those who are organized and involved in the problem and who decide to act on it;</li> <li>the intervention process itself – the action – is used to transform reality to expose, reflect on and build knowledge on problems and power relations;</li> <li>reflection and knowledge generation is done by those implementing the actions and not by external actors; and</li> <li>learning strengthens agency and control over change among those directly affected in the health system and in the community.</li> </ul> <p>Participatory action research provides a form of evaluation directly from the lens of those involved in and affected by the transformation.</p>
Policy analysis and historical analysis – examines the evolution of policies, institutions and programmes over time	<p>Shares interest in the drivers of policy and change but it differs in...</p> <ul style="list-style-type: none"> <li>drawing from direct shared experience and analysis of specific social actors; and</li> <li>building power of those social actors in policy or institutional transformation.</li> </ul> <p>In explicitly integrating transformation / action by those involved, this approach directly engages with the interests and power of actors in policy processes.</p>
Cross country analysis – includes comparison of multiple countries or systems to identify generalizable learning	<p>Shares the desire to explore learning from real experience but applying participatory action research differs in that ...</p> <ul style="list-style-type: none"> <li>learning within each setting is built through participatory action research approaches.</li> </ul> <p>Participatory action research faces similar challenges on generalizing across contexts and settings (discussed further in <i>section 3.4</i>). May provide a form of cross country learning using participatory action research approaches.</p>

Source: Authors



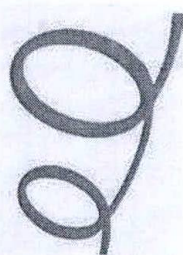
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## Part two

# Methods

*Part two cover page photo:  
Participatory gender-responsive research focus group, Kyrgyzstan*



## Part two

# Methods

*I could not consider myself a scientist, even less a human being, if I did not exercise the 'commitment' and feel it in my heart and in my head as a life-experience, Erfahrung or Vivencia. .... There is no need to make any apology for this type of committed research.*

Orlando Fals Borda (1995:5)

Research methodology is a strategy or plan of action that shapes our choice and use of methods and links them to the desired outcomes (Baum, 2006). Health systems and policy research, as discussed in the previous section, requires methodological pluralism, including approaches such as participatory action research. As a research methodology, participatory action research uses many methods. Both qualitative and quantitative, these methods include mapping, opinion polls, testimonies, ranking and focus group discussions, as further discussed in this section.

As outlined in *Part one*, participatory action research aims to construct research questions, methods, interpretations and products within processes that invert who frames and is framed by problems. The traditional objects of research become 'architects of critical inquiry' and the location of power is shifted at every stage of the research process. This process can be emancipatory and transfer power although, as noted earlier, not all forms of participatory research achieve this. Participatory action research processes and methods seek to review and validate the experience of those directly involved in issues studied, to problematize, reflect on, re-articulate and transform systems and to learn from such actions (Leung, Yen and Minkler, 2004; Cammarota and Fine, 2006).

Both the processes of participatory action research and many of the methods used may not be well known in the traditional scientific community. This approach is seldom taught in medical or health

science courses. This knowledge gap can lead to the mistaken perception that it is 'an inferior approach to research' or 'not real science'.

This section explains the processes, steps, methods and tools used and how these are organized to achieve the key features of participatory action research described above and the knowledge it generates. While the broad processes remain consistent across contexts, the specific methods and tools used may be highly context and group dependent. Disembodying the tools from these processes and using them in an isolated manner to extract evidence in processes that do not shift the subject-object relations or address other features of the approach would not make this research 'participatory'.



*A group of people work out a participatory scoring exercise. Indonesia*

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## 2.1 The participatory action research process

This section outlines the research process for applying the core principles of participatory action research.

The key elements in participatory action research, outlined in *section 1.1* and listed in *Box 9* below, are used to select the methods or tools for specific areas of inquiry. The broad process was summarized in Figure 1 in *section 1.1*, that simplified the spiral of repeated cycles that guides the steps in inquiry and action and informs the design of methods and tools. This part of the reader provides information on the methods and tools used for these steps:

- Systematizing experience by collectively organizing and validating experience;
- Collectively analysing and reflecting on patterns, problems, causes and theory;
- Reflecting on and choosing action, considering alternative courses of action and identifying actions;
- Taking and evaluating action, and reviewing its course and consequences; and
- Systematizing the learning from these processes – organizing, validating and sharing new knowledge.

By virtue of the dialectic between theory and action, participatory action research is not a neat linear process. This reader provides examples of how the methods and tools have been used to fulfil the process in Figure 1. Participatory action research does not

have discrete phases from opening questions to final answers in steps of design, data collection, analysis and reporting. It is a more continuous process of self-reflexive inquiry. It recognizes the complexity of relationships between causes and outcomes and the probability of unexpected outcomes within the process. It allows for uncertainty and evolution in the methods, to be able to respond to what emerges in the different stages of the process. In so doing, the researcher or facilitators are constantly guided by the key principles in *Box 9* in identifying the best methods and tools to take the process forward, rather than rigidly implementing the tools. This responsiveness to reality, found also, for example, in grounded theory, means that those involved triangulate and crosscheck evidence and use plural methods to extract learning.


## 2.2 Overcoming the subject-object distinction

Given the principle of overcoming the subject-object distinction and being located within a struggle over lived reality by those affected, a key starting point and platform for participatory action research is the community or social group or organization within which the inquiry is located. This section discusses how this is achieved in the research process.

The term ‘community’ often masks a heterogeneous group of people, with many internal differences along the lines of wealth, gender, age, religion and culture, for example. These social differences are associated with power relations between people

### Box 9: Principles of participatory action research

Participatory action research ...

- 
- 1 is located within and involves those directly affected by the conditions or systems in focus (the principle of *no delegation*);
  - 2 is located within the context of struggle over conditions or systems and uses this understanding to transform them;
  - 3 takes place within those directly affected that have an organizational potential to act on issues;
  - 4 builds theory by reflecting on the collective lived experience (*vivencia*) of that group;
  - 5 systematizes local experience and organizes shared collective analysis on relationships and causes of problems;
  - 6 creates a dialectic between theory building and practice for those involved, systematizing and validating the knowledge developed from action and using that knowledge to further transform conditions, systems and institutions;
  - 7 shifts power towards those affected to know, problematize, understand, act and transform.

in that community, as discussed in *section 1.5*. Navarro suggests that a community should be seen as a set of power relations within which people are grouped (cited in Cornwall and Jewkes, 1995). Competing, contested and changing values, needs, agendas and solutions emerge depending on the interest groups involved and how their intentions are interpreted. The methods used in participatory action research seek to identify these differences where they are relevant to the problems under inquiry and to collectively overcome the distorting effect of particular individuals or groups dominating in sharing or interpreting experience (Cornwall and Jewkes, 1995).

The *subject-object* distinction is crucial in participatory action research and a point of divergence between this and many other research paradigms. Other paradigms assume that social science researchers can study and measure society objectively, ignoring the fact that they are a part of society. Such objectivity is considered impossible in participatory action research because researchers cannot avoid the influence of their own social context and values on what they choose to study and the questions they explore. The viewpoints and values that guide inquiry in participatory action research should thus be made explicit, as they should be for other social science (Bourdieu et al., 2013).

The principle of *no delegation* implies that the main subjects of the study are those directly involved and not their representatives or professionals. This influences both the nature of the 'researcher', as discussed in *section 1.4*, and the subject-object relations, although with some variation across different forms of participatory action research. In

the Italian workers' model, described in *Box 14* in *section 2.3*, community actors take the leading role in research and academics or technicians play a complementary role in facilitating technical inputs (Oddone et al., 1977). In the Colombian school (Fals Borda, 1987), researchers make an ethical and political compact with communities to form a joint research team, while others construct a common ground of mutual confidence between communities, professionals and academics (Baum et al., 2006).

Rather than the random sample used in positivist approaches, participatory action research uses a purposive organization of a *homogenous group* or a group with shared conditions. As noted earlier, no community is totally homogenous and even within similar social groups people have different assets, concerns, power or values. The term 'homogenous group' does not negate this. It refers to a social group that shares the same conditions and has the basic organization to discuss and validate individual members' experiences collectively, notwithstanding their internal diversity, and to take action based on that discussion.

What constitutes a homogenous group and who initiates it is variable. For example, in the workers' model (Laurell et al., 1992: *Part five paper 7*) the groups were organized (unionized) workers within common work processes who invited academics to participate. Academics or professionals with links to communities may also initiate the process, sometimes through long-standing links with a particular social group or community. Whatever the instigation, a 'homogenous group' is deliberately constituted. Based on shared objectives and values and a shared capacity to act, it takes deliberate measures to build



#### **Box 10: Social groups included in participatory action research on reproductive health in India**

In India a small non-governmental organization worked with rural women and traditional birth attendants to address reproductive health concerns in the area through both use of local medicines and promotion of health practices. Rural women and traditional birth attendants were the two main social groups included in the process and local health care workers were brought in as a further group.

Through a process of reflecting and mutual learning over several years, participants built on local knowledge and resources and shared local medicinal knowledge to develop an effective, self-reliant, health care delivery system. Efficacious remedies were tested and extended by establishing nurseries where women could choose seedlings for home use. Visual techniques for taking case histories and notes were developed by the women and visualizations, such as explorations of their knowledge and perceptions of their bodies, were used in workshops.

*Source: Cornwall and Jewkes (1995)*

a common understanding about the problem to be resolved. Since action is essential to participatory action research, a homogenous group is able to act and to evaluate the results of its strategic actions (Othieno et al., 2009: *Part five paper 5*).

The India example in *Box 10* on the previous page, and the Zambia case (Mbwili-Muleya et al., 2008: *Part five paper 6*) included two groups: a geographically circumscribed community – rural women (India) or urban residents of a specific area (Zambia) – and a group of local health workers – traditional birth attendants (India) and primary care nurses (Zambia). The explicit aim in these cases was to build shared knowledge and action across the groups, through processes that allowed for separate inquiry and reflection within the community and

among health care workers, and then for dialogue across groups (as more fully elaborated in the Zambia case). In both processes, the knowledge and action and the power shifts deepened in the medium term (two to five years) with the repeated cycles of participatory action research.

As in the examples given, the participatory action research process may bring together different actors, each with their own knowledge and experiences, to work together in dialectical processes to produce new forms of knowledge. Given the power dynamics involved, the possible differences in experience and perception within the groups involved need to be recognized and considered. The initial stages involve listening to individual observations, before these individual inputs are accumulated and discussed collectively by the group, in a process of validation by consensus. The tools used to draw out experience need to be accessible and appropriate to the social groups concerned, so the involvement is not just token. These tools are further discussed in *section 2.3*. Examples of how the methods factor in accessibility and organize the collective accumulation and validation of individual views in the group are given in *Box 11* below.

To guarantee that the information the research generates corresponds to the collective experience of the group and is not simply a sum of individual subjective observations, the evidence gathered is

#### SEE PART FIVE: PAPER 7

Laurell et al. (1992), as with much other participatory action research in the period in Latin America, constructed homogenous groups from organized, unionized workers, who invited academic researchers to support their inquiry.

#### SEE PART FIVE: PAPER 6

In Mbwili-Muleya et al. (2008) participatory action research explored factors affecting community involvement in planning local health systems and ways of strengthening their participation at four health centres. The two groups brought together were community members from the catchment area of the clinics and the health workers at those services.



### Box 11: Methods for drawing and validating experience from homogenous groups

Diagramming and visual sharing are common more accessible ways of drawing experience that allow for sharing evidence within the group. With a questionnaire survey, information is appropriated by the outsider. The words of the person interviewed are owned by the interviewer. In contrast, with visual sharing of a map, model, diagram or units (stones, seeds, small fruits) used for ranking, scoring, counting or quantifying, all those present can see, point to, discuss and alter objects or representations.

Ranking and scoring have long been part of the repertoire of social anthropologists. For example, in eliciting perceptions of health needs, an initial list can be made with inputs from each person individually, to allow for a diversity of experiences and views. A process of ranking can be done by giving each person beans or stones to place against the listed need they consider to have the highest priority, the greatest burden or whatever the agreed criteria used.

While this on its own can be used to reach a representation of the collective view (with the needs ranked by the number of stones received), a further process of triangulation can take place where the list is interrogated and discussed, with people crosschecking and correcting each other.

The learning is progressive. The information is visible, semi-permanent and public, and is checked, verified, amended, added to and owned by the participants.

Source: Loewenson et al. (2006)



## Box 12: Validating group observations in participatory mapping and modelling

In participatory mapping and modelling, villagers draw and model their villages and resources, deciding what to include, and debate, add and modify detail. Visual literacy is universal. Everyone can see and contribute to what is being 'said' because it is being shown.

In shared diagramming, information may represent, for example, seasonal changes in dimensions such as rainfall, agricultural labour, income, indebtedness, food supply and migration. Paper can be used for diagrams but the ground and other local materials have the advantage of belonging to the group – media that villagers, whether literate or non-literate, can command and alter with confidence. The diagram presents a visible shared checklist or agenda owned by those producing it.

The process of constructing a visual representation is in itself an analytic act, revealing diverse issues and connections that people may not have previously thought about. Activities to interpret the diagrams or 'interview the maps' play an important part in the process. Visualization facilitates, rather than replaces, discussion, and is used to facilitate a shared analysis of the evidence.

Source: Chambers (1994)

*validated by consensus.* That means registering only observations that the whole group recognize as valid.

Unlike in experimental forms of research, the validity of the process is not strengthened by the community being 'blind' to the nature of the inquiry but by how effectively the method and tools genuinely draw out, respect and share the different forms of experience, knowledge or perceptions 'around the table'. This includes engaging with different knowledge systems (indigenous or professional) and facilitating expression of different cultural and social meanings in the process.

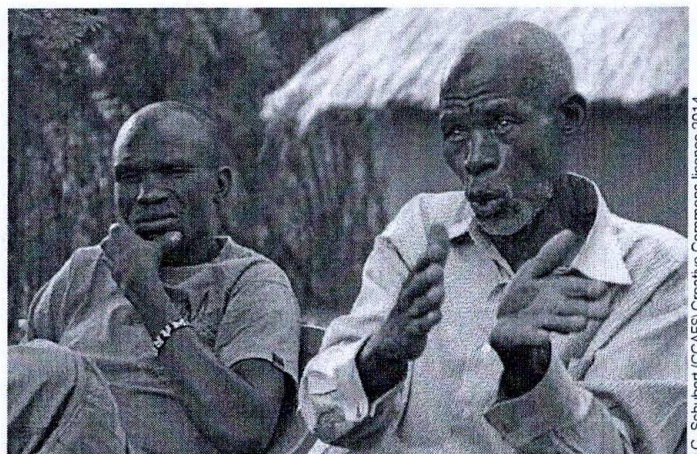
Validating group observations through collective discussion is driven by consensus. However this does not negate differences in perception and experience. Collective discussion of evidence is done in a manner that explores, interrogates and draws learning from diversity and differences. This means using methods involving looking for, discussing and learning from exceptions, contradictions and differences. *Box 12* above gives one example of a method for exploring and recording individual observations, reviewing them collectively and exploring diversity to reach a consensual validation. Chambers (1994) expresses this as seeking variability rather than averages, to 'maximize the diversity and richness of information'.

As with all research, how methods are applied in practice may not match the ideal. The sources of bias or error that can arise are discussed in more detail in *sections 3.2 and 3.3*. However, inherent within the process, a strong test of validity for the

method is to what extent it gives those involved an opportunity to:

- 1 input their own experience;
- 2 check, correct and reach a shared consensus on collective results of the group; and
- 3 discuss and reflect on patterns and differences to reach a consensus on the collective findings.

As noted earlier, where there are differences between groups involved that bring 'unequal players to an uneven table' (Minkler, 2000), it can be important to sequence processes so that each group has the opportunity to reach its own collective findings within the group, before the dialogue takes place across groups to examine and reflect on the common and different findings of each, and to identify the shared analysis across both.



*Discussing gender roles and responsibilities in Western Kenya*

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## 2.3 Methods and tools for gathering evidence

This section explores the methods and tools that participatory action research uses in:

- problematizing, validating, collectively analysing and reflecting to build new knowledge; and
- reflecting on and learning from action.

As shown in the methods used for drawing out the experiences of social groups, participatory action research methods involve a number of shifts:

- From individual to group evidence and analysis – with triangulation both instant and observable;
- From verbal to visual evidence – with visual methods an ‘equalizer’, especially when they use familiar media and raise questions and differences for discussion; and
- From measuring to comparing, to provoke reflection and analysis, and to elicit trends, differences and changes (Chambers, 1994).

Various methods and a wide range of tools can be useful for such processes. Table 5 on the following pages shows examples of methods and tools, with further detail provided in the papers in *Part five*, in the examples in boxes and in the references cited below the table. This reader does not provide detailed information on how to implement these methods as this can be found in methods guides and toolkits. For many of the methods listed, information can be found in EQUINET’s methods toolkit, *Organizing people’s power for health: participatory methods for a people-centred health system* (Loewenson et al., 2006) available online at [www.equinetafrica.org](http://www.equinetafrica.org). In other cases the table refers to papers or websites where further information can be found.

### SEE PART 5: PAPER 9

Inmuong et al. (2011) describe how sub-district administrative organizations that are small-scale local governing structures in Thailand embedded participatory methods within health impact assessment tools to implement their legal duty to control health hazards.

In 2005/2006 several of them developed cooperative activities between researchers and community representatives using participatory mapping followed by community participatory workshops to review the findings and propose health-hazard control regulation and appropriate practices to control the risks identified.

The methods listed have many variations, depending on the context within which they are being used. Inmuong et al. (2011: *Part five paper 9*) describe, for example, how these methods were used in fulfilling legal obligations to carry out health impact assessments.

The way the methods are applied also vary in different contexts. For example, transect walks, described in Table 5, can be walks or ‘windshield’ tours, involving walking or driving around a neighbourhood, documenting observations and impressions or using a checklist to indicate assets or risks identified. The California Centre for Physical Activity (<http://www.cawalktoschool.com/checklists.html>) has a multilingual walkability assessment checklist to help residents answer the question, ‘how walkable is your community?’ The tool includes action steps so residents can identify actions to improve the walkability and safety conditions of their neighbourhood (Minkler et al., 2012; California Walks, undated). *Box 13* on page 49 describes the use of mapping in different settings. Emmel and O’Keefe (1996) describe the use of seasonal mapping and wealth and asset mapping in analysing health delivery and access to services in Mumbai (‘Bombay’ at the time the paper was written). A further example of mapping and transect walks in systems for urban public health is included from Minkler et al. (2012), while the workers’ model in *Box 14* shows participatory mapping applied in the form of a risk map, as shown in Figure 3.

As noted earlier, the methods within individual steps do not on their own fulfil the participatory action research principles of knowledge generation, power shifting and transformation. The full process and step sequence of methods interact cumulatively, each adding a dimension and details to qualify, enrich, triangulate with and pose contradictions or patterns for reflection. Taken together, the whole becomes more than the sum of the parts.

In Table 5, some methods are more useful for drawing out experience, others for analysing causes and relationships, others for determining priorities for action and so on. A central notion of such processes is that knowledge obtained by sequencing the different methods is qualitatively different from and more comprehensive than that based on individual questionnaires (or individual participatory tools) because it allows an understanding of the complexity of processes and their interrelations.

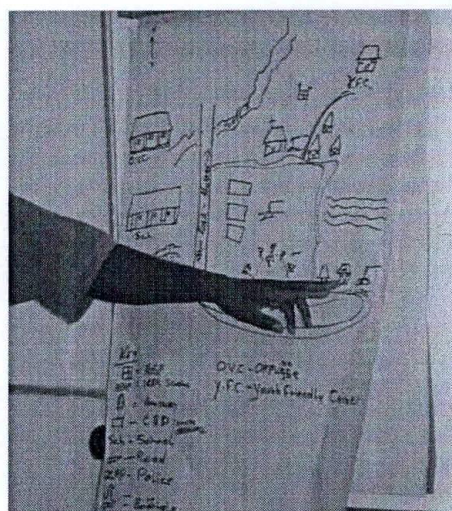
**Table 5: Methods, tools and their use in participatory action research processes**

METHODS	USE IN THE PAR PROCESS
<p>In <b>participatory mapping</b>, those involved draw one or more maps of their area or of the setting for the inquiry and particularly noting the physical conditions. This includes risk and hazard maps, such as at workplaces or in neighbourhoods. An example is shown in <i>Box 14</i>, the 'workers' model' and discussed in <i>Part five paper 7</i>.</p> <p>A range of mapping and other tools used in a workplace context can be found in <i>Barefoot research: a workers' manual for organizing on work security</i> (Keith et al. 2002), available at <a href="http://www.tuc.org.uk/workplace-issues/health-and-safety/barefoot-research">http://www.tuc.org.uk/workplace-issues/health-and-safety/barefoot-research</a>.</p>	<p>Used to draw and validate information on conditions and experience.</p> <p>May be used to identify problem sites and risk areas, to analyse service access and benefits by social groups, when combined with social mapping, and to identify proposals for change in conditions and services.</p> <p>Maps may be added to at different stages of the process to present new, complementary information, to support planning and to monitor and evaluate action and transformation.</p>
<p><b>Social mapping</b> follows a similar process as participatory mapping but is more explicitly focused on social characteristics, including population, social group, health and other household characteristics. It includes asset, well-being and vulnerability mapping. The latter may be important to identify disadvantaged groups for inclusion in the research process. See for example Figure 2 in Maalim (2006: <i>Part five paper 10</i>) mapping seasonal nomadic movements.</p>	<p>Social mapping can be progressively engaged with, as in all participatory mapping, to identify key social groups and processes, different needs, preferences, disease distribution or other health information for discussion, negotiation and reconciliation of priorities or to identify individuals to involve or engage in the work.</p> <p>Social maps can delineate areas and groups for up-to-date household listings used for well-being or wealth ranking for health financing decisions, as was done by Aryeetey et al. (2013: <i>Part five paper 18</i>).</p>
<p><b>Maps</b> may be further developed through a <b>transect walk</b> or <b>participatory observational surveys</b> to add information to social maps and discuss observations.</p> <p><b>Transect walks</b> are systematic walks across the community allowing participants to see a range of features, resources and conditions in the area. Generally they are done after map drawing and are used to validate information gathered from participatory mapping. See for example <i>Box 13</i> and <i>Part five paper 9</i>.</p>	<p>Used to generate evidence on conditions, services or assets, or to validate evidence, quantify or inform reflection on problems and action.</p> <p>For example, Chambers (1994) describes a participatory resource map that rural villagers did of a degraded forest area. The map and a rootstock census of quadrants in the forest, led to calculation, debate, analysis, decisions and action in the community on the numbers of trees to be planted, the proportions of different species to be planted, and the numbers of each required in tree nurseries.</p>



Participatory mapping, Thailand

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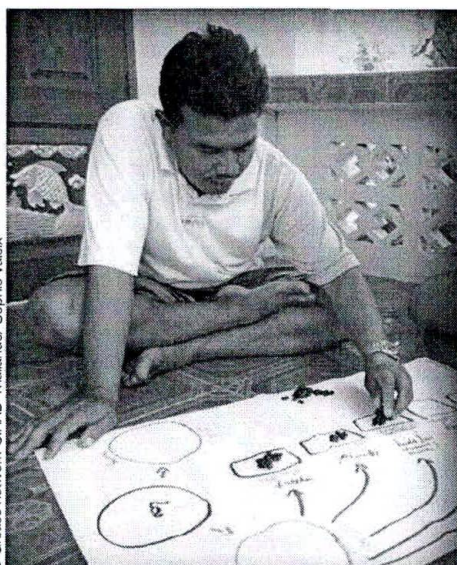
Social map, Zimbabwe

© TARSC 2011

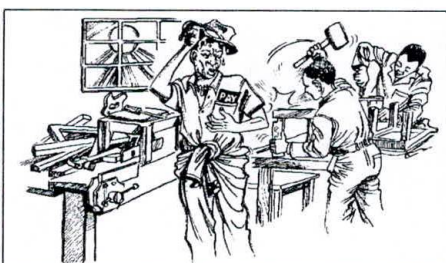


Transect walk in Malawi

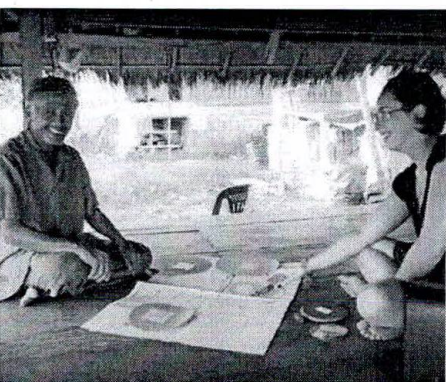
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Use of proportional piling, similar to pocket charts, Thailand



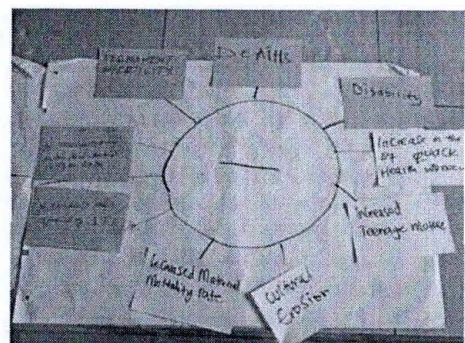
A picture code, Zimbabwe



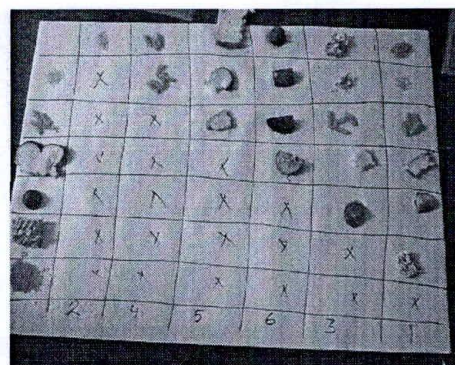
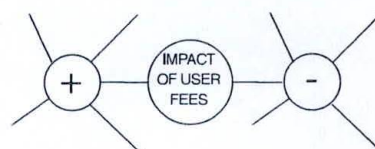
Using venn diagrams, Thailand

METHODS	USE IN THE PAR PROCESS
<p>A <b>pocket chart</b> is an investigative tool used to collect and tabulate data from the community level, such as where people collect water or the networks of information exchange. Poster-size charts contain 'pockets' of cloth or paper inserted in each cell in a matrix, with simple drawings identifying the subject of each row or column. Participants 'vote' on topics, such as health service features, by placing counters in the pocket that indicates their situation or preference. See the 'how to' guide at <a href="http://collections.infocollections.org/ukedu/en/d/Jwhs046e/7.3.html">http://collections.infocollections.org/ukedu/en/d/Jwhs046e/7.3.html</a></p>	<p>Pocket charts are used during group discussions to tabulate information. They are a useful visual method for participants where literacy levels may be lower. For example, by putting different urban water sources in the columns and different uses of water in the rows, the frequencies of sources and use can be tabulated. The findings are discussed within the community, including variations across seasons, groups or areas. By changing the symbols on the headings, the chart can be reused for many issues.</p>
<p><b>Picture codes</b> are single pictures that reflect situations, conditions or problems that can be used for triggering discussion. Examples are given in the EQUINET PRA toolkit (Loewenson et al., 2006:34). This is now further developed through community photography (<b>photovoice</b>) as used by Young and Barrett (2001: <i>Part five paper 14</i>) and also using video (<b>videovoice</b>).</p>	<p>Used for a wide range of purposes in the participatory action research process as triggers discussion on conditions, system performance, causes and actions to be taken. Can be used to raise and discuss sensitive or buried issues, such as on sexual and reproductive health services, or responses to substance abuse.</p>
<p><b>Venn or chapati diagramming</b> consists of a series of interrelated circles that indicate the relationships, status in the community and interactions between social groups, actors or institutions. The size of the circle indicates importance and its position and distance from the central group or institution and other circles indicates the relationship with the central and other actors.</p>	<p>Provides a means of mapping, reviewing and discussing the features of the diagram to examine relationships between actors and services. Can be used to examine patterns and preferences in use of services, information flows between institutions and actors, access to services and other issues affected by relations in health systems. See for example <i>Part five paper 11</i>. Can be linked with <b>flow charts</b> to map interactions or flows that support well-being or raise risks for health or uptake of services. For example venn diagramming has been used to show possible water and food contamination routes in communities to discuss how to prevent these risks.</p>

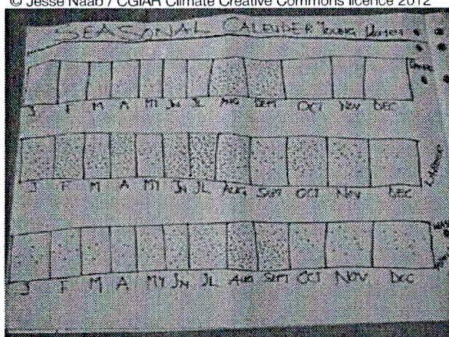
METHODS	USE IN THE PAR PROCESS
<p><b>Spider-grams</b> are visual tools for identifying and analysing relationships. In the spider diagram the 'body' may be the issue of focus, such as user fees or use of health services by adolescents. The legs would then reflect different factors that affect or are impacted by that situation. The separation of factors (spider legs) allows for follow up processes, such as ranking problems or consequences, or showing the links across them. In the diagram on the right two spiders are used – one for positive and one for negative impacts of user fees, used for example in discussing who gains and loses from this policy.</p>	<p>Used to draw evidence on determinants or outcomes from a situation or condition, to problematize issues and to analyse the links across these determinants or outcomes as an input to problem solving. Can be used to draw out evidence on health problems affecting a social group, factors affecting use of particular services, consequences of access to a social determinant of health and so on. It can also be used to compare across different social groups (using different diagrams for each).</p>
<p><b>Resource maps</b> show resources, sites and forms of income generation in a community, neighbourhood.</p>	<p>Can be used with other approaches to analyse and decide on action, such as to relate resources to need or to identify assets to draw on in solving problems raised.</p>
<p><b>Well-being ranking, preference ranking, matrix ranking and matrix scoring</b> are various forms of ranking and scoring. Wellbeing ranking in its most common form starts with social mapping to identify households. These are written on individual cards that small groups sort into piles (three or four pile sorting) according to particular categories of household features (for example, wealth) or well-being they decide upon. See an example in <i>Part five paper 11</i>.</p>	<p>Used for valuing and scoring parameters, such as the use of different contraceptive methods, satisfaction with services, payments made, comparison of provider performance. Comparisons are made directly through the scores or by grouping or positioning other items on those numbers. Hence for example, household cards can be grouped according to their judgements of personal or household conditions or by placing them on a scale, such as on a rope symbolising households climbing out of poverty.</p>
<p><b>Pair wise ranking</b> is a method of comparing each item on a list with the other items in a systematic way. Each choice is compared with all others, one by one. For detail on how to implement it see <a href="http://pubs.iied.org/pdfs/G01675.pdf">http://pubs.iied.org/pdfs/G01675.pdf</a> The final ranking and the information shared while doing a ranking and scoring exercise both contribute to learning.</p>	<p>Pair wise ranking determines the preferences of individuals or groups. <b>Matrix ranking</b> goes further to elicit the preferences and to draw out and examine the criteria that different people use in choosing preferences from the alternatives.</p>
<p><b>Collective questionnaires</b> use an indicative questionnaire to orient discussion that is applied and interpreted by workers or union officials. See for example their use in <i>Part five paper 7</i>.</p>	<p>Addresses all stages of the process to gather, organize, reflect on and use evidence as a bargaining tool.</p>



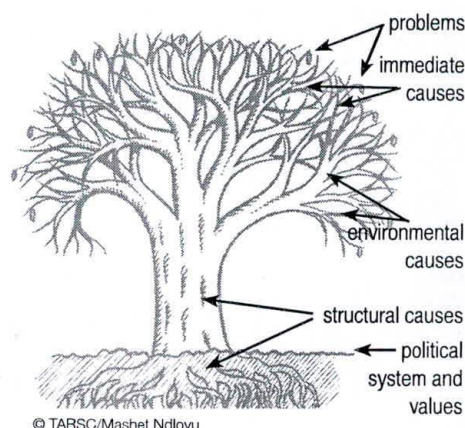
Spider diagram, Uganda



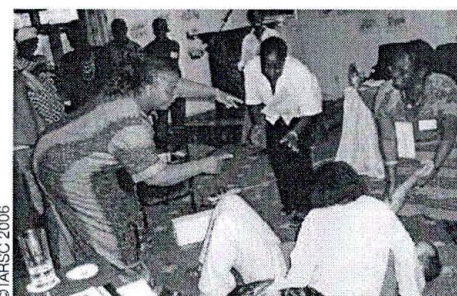
Preference ranking, Nepal



Female youth seasonal calendar, Ghana



© TARSC/Mashet Ndlovu



Human sculpture on experiences of the health system, Tanzania

METHODS	USE IN THE PAR PROCESS
<p><b>A seasonal calendar</b> is drawn up by participants to show the seasons experienced annually and movements or changes associated with this. Can be used over successive years to document changing patterns of health responses, shifting burdens or trends. See for example its use in <i>Part five paper 10</i>.</p>	<p>Relates information drawn from delegates in an earlier 'listening stage' to seasonal patterns to analyse relationships. For example they were used to map the movements of a nomadic community during the wet and dry seasons and the common diseases (disease patterns) that the community experiences in each season to propose service organization.</p>
<p><b>Daily work schedules</b> as developed by different social groups outline the daily activities of different sections of the community. They cover the routine activities, roles and functions performed within a 24 hour period, as in <i>Part five paper 14</i>.</p>	<p>The schedules are used to determine the daily workloads of different members of communities. They draw out sometimes hidden information on the time taken for basic functions or seeking services, time conflicts, and the distribution of workloads.</p>
<p><b>Life histories, narratives and storytelling</b> use structured stories to represent experience from micro to macro level, including reflecting on past and current conditions. Coming from a tradition of ethnography, anthropology, testimonial and cultural studies, they produce a hybrid way to present reality as experienced by the 'researcher as narrator'. 'Tellers, writers and actors' do this to pass on these experiences and learning, by word of mouth, by pictures or by written or multimedia forms, for the benefit of 'listeners, readers and watchers'. See for example <i>Box 16</i> and <i>Part five paper 8</i>.</p>	<p>Can be an effective method for exploring practice, settings, situations and their resolution or actions and to show learning from experience. Useful for communicating complex contexts and situations, and to support interpretation of other evidence. Can be used for trend analysis, evaluations, or review of cycles of improvement. Evaluative narratives compare discrepancies, particularly between what is and what is not valued. Used with the 'but why' method (EQUINET PRA toolkit, Loewenson et al., 2006: 43) can explore reasons for observations.</p>
<p><b>Problem trees and flow diagrams</b> offer a structured way of getting at the various levels of a problem. The analysis is done collectively and discussed (sometimes matched with 'but why' questions outlined above) to identify reasons for analyses.</p>	<p>Used for analysing causes. As a tree, for example, the pods are the problems; the branches that hold them are the immediate causes; the large branches the next level of causes; and the trunks or roots are the underlying structural causes. The ground is the political systems and values that are the context for the structural causes.</p>
<p><b>Human sculpture</b> is used to portray a situation by people taking 'roles' of actors or institutions involved in a health problem or situation, with the sculpture showing how they relate to each other. The location, positioning and height of the actors reveals dimensions of power, interaction and so on. Drama, and stop drama can also be used as a code. See <i>Box 15</i>.</p>	<p>Useful in analysing relations in health systems and identifying changes or transformations to be made in other institutions and actors to address the needs of specific groups in the sculpture. Drama can be used as a code to draw and discuss evidence and propose changes to various dimensions of functioning of systems.</p>

Sources: Chambers (1994); Cornwall and Jewkes (1995); Keith et al. (2002); Loewenson et al. (2006); Maalim (2006); Chambers (2007); Wadsworth et al. (2007); Peacock et al. (2011)



## Box 13: Participatory mapping and transect walks

### Participatory mapping of women's health in India

This participatory research used in a Bombay (sic) slum of 33 households, Budh Mandir, aimed to identify the incidence of different health problems within the households at different times of the year. At the first participatory meeting, the women from all households in the slum drew a map of the area which they considered to be their neighbourhood. They then drew a more detailed survey map. They checked and corrected this for each household, with information on the broad demographic and economic characteristics of the households and the incidence of specific health problems mapped by drawing on the women's knowledge.

Seasonal maps were used to then understand how these conditions changed over time, with crosschecking of maps between the women. The participatory exercises exposed differences in perceptions between professional health deliverers and the women of Budh Mandir, and provided data at a household level about the incidence of disease at different times of the year.

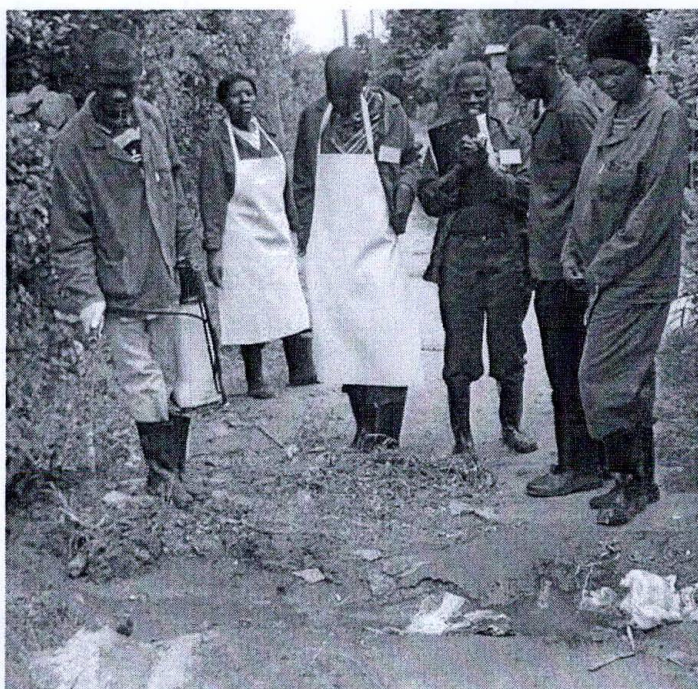
*Source: Emmel and O Keefe (1996)*

### Participatory mapping and surveys in the Healthy Neighbourhoods Project, California

The Healthy Neighbourhoods Project, was implemented through the Public Health Department in the west part of Contra Costa County, California. A small number of community members who were respected by their peers were familiarized with neighbourhood asset and risk mapping tools. They used them with community members in their neighbourhood and then convened in a local park to consolidate their findings on a large map. Through both a resident-conducted community survey and community dialogues, residents identified key issues they wanted to address (for example putting in speed bumps, restoring the night bus service and improving street lighting). But they also built on their own assets to help secure these changes, researching the issues, learning about key decision makers and leverage points. They then wrote letters, engaged in testimony and in other ways worked together to bring about change. In addition to securing the speed bumps, night bus service and many other changes they had worked for, this project helped spawn replication projects in several other neighbourhoods.

*Source: Minkler et al. (2012)*

As noted earlier, the research design thus reflects broad steps that advance the stages of the cycles of participatory action research shown in Figure 1, with methods and tools applied at each step. As an example of the *whole* process, one of the most systematic and transformational approaches, changing both knowledge and health conditions, is the workers' model, shown in Box 14 on the next page with each step clarified.



*Community volunteers contact tracing during a cholera outbreak, Zambia*

© Idah Zulu, February 2009



### Box 14: The workers' model

The most significant experiences of participatory research on working conditions, work organization and work-related health problems was developed in Italy in the mid-1960s. It was applied by workers at thousands of workplaces and promoted by the factory councils of the unions (CGIL, CISL, UIL) (see Section 1.2). It explicitly aimed at shifting power relations between bosses and workers.

The Italian workers' model was originally elaborated by a group of workers and union activists at a Fiat factory, together with psychologists, physicians, sociologists and students. It responded to the upsurge in labour movement activity in the autumn of 1969 and aimed to transform the collective questionnaire that had been used for a survey on working conditions and health carried out at 366 workplaces in 1967. The idea was to make it into a widely-applied participatory research instrument (Laurell, 1984). The model is a method of generating knowledge for change. Workers' subjectivity or experience is central in building an understanding about working conditions and work hazards or loads, not just to identify the risks for workers' health but to enable workers to transform their working conditions.

As a process, the first step provides a means of systematizing workers' experience. The hazards or loads of the work environment are organized into four 'risk groups':

- those present inside and outside the workplace, for instance: noise, temperature, illumination, humidity and ventilation;
- those typical of the workplace, for instance: dust, gases, vapours and radiation;
- those producing physical fatigue; and
- those provoking mental fatigue.

The risk groups correspond with workers' experience and representation of the work environment and are also associated with scientific knowledge, providing a 'common language' between workers and professionals. The main innovation of the model is, however, the process of generating knowledge. This is based on four basic concepts: the principle of no delegation, the workers' experience (or subjectivity), the homogenous group and validation by consensus.

The workers' unstructured experience is turned into systematized, conscious and shared knowledge through a questionnaire based on the four risk groups. Their experience is collectively discussed and problems resolved by a group of workers that share the same working conditions and have the basic organization that enables action. This is termed a homogenous group. The observations are validated by consensus – only those observations that are recognized as valid through collective discussion by the group as a whole are registered. Together with the questionnaire a risk map is drawn up as a graphic representation of the work process, its hazards or loads and workers' health problems. This is used as a tool to communicate with other workers and serves as an instrument to follow changes – positive and negative – at the workplace.

In a second phase of the investigation some of the elements detected by the collective questionnaire are verified or quantified using conventional techniques to measure exposure or health outcomes.

In the next step, workers determine, again through collective discussion, the priorities for change and the strategies to achieve this, ranging from mobilizing to collective bargaining. That change may involve conflict is an inherent part of this conception of knowledge for action. Furthermore, the homogenous group not only produces knowledge but the members use that knowledge together with prior scientific knowledge, fusing research and learning into a single process. Knowledge obtained through this process is considered qualitatively different from and more comprehensive than that based on individual questionnaires; it gives an understanding of the complexity of processes and their interrelations. Formulating priorities for change and strategies to achieve it consolidates the knowledge and demonstrates its practical utility.

Many such studies in different workplaces were not formally published but were used in collective bargaining or as background evidence for local action. There are, however, documented and published studies on the steel, car, metal, chemical, textile, shoe, petrochemical, clothing, ceramics, food and cement industries as well as on construction, agricultural, hospital, transport and electricity workers, particularly but not exclusively from large enterprises (Laurell, 1984). Workers participated actively not just in decisions about what to study but also in measuring and interpreting the data.

The published studies are authored by health working groups at a specific factory council, by unions and some by individual professionals and/or workers. The work was published in union booklets, trade union books and as articles in union or conventional scientific journals.

A special journal, *Medicina dei Lavoratori (Workers' Medicine)*, using the format of a conventional scientific journal, was started by the unions' Centre for Research and Documentation on Working Risks and Health Damage in 1974 and became the main publishing forum for these studies. A video documenting the work can be found at <http://www.youtube.com/watch?v=5-efXmeNP0w&feature=youtu.be>

The studies created a widespread consciousness about the importance of work for health and raised the social visibility of the research, the evidence found and action around it. This influenced the conception of public health and of health institutions, evident in the 1978 public health policy, known as the Sanitary Reform. They had a direct impact on collective bargaining agreements and labour law, with recognition of workers' rights to carry out their own studies on health and working conditions and on information rights at workplaces (Laurell, 1984). The unions created their own occupational health institutions and a research and documentation centre. The combined effect of all these changes contributed to a decline in work-related health problems and work accidents (Berlinguer, 1979).

Source: Loewenson, Laurell and Hogstedt (1994)

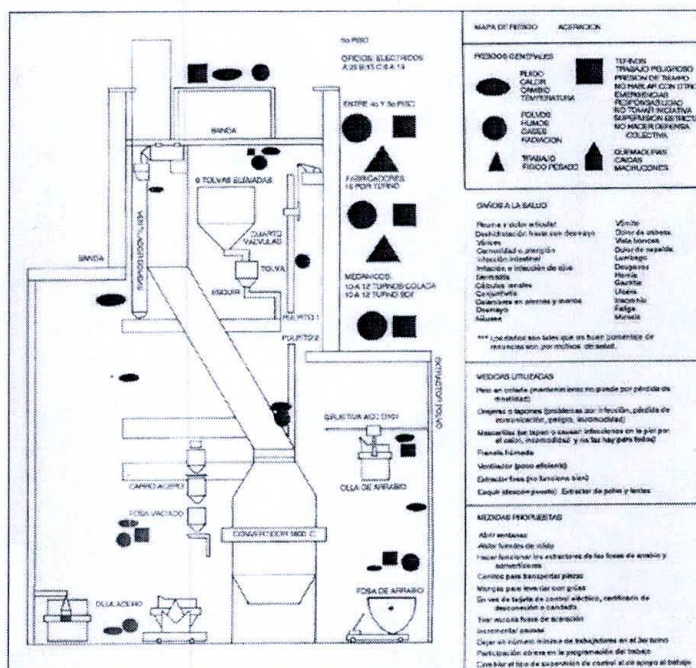
Retaining these broad steps, the specific methods in the workers' model have been modified and further developed in different contexts. In Latin America a collective questionnaire was applied in workplace health. It covered five broad themes:

- 1 the characteristics of the work process;
- 2 its hazards or loads;
- 3 the health damage, understood as disorders, and the diseases they provoke;
- 4 the existing health protective measures; and
- 5 the protective measures proposed by the workers to protect and promote health.

In each of these themes the collective questionnaire posed a series of 'questions or discussion themes'. These orient the discussion but leave sufficient space for workers to express their perceptions since there are no closed questions. The information gathered intentionally related to a group of workers and not to individuals and was mainly qualitative. However, it allowed for an estimation of the magnitude or intensity of the hazards or loads, the proportion of workers exposed and also of the proportion of workers that experience health damage. The risk maps make a graphic synthesis of these elements (described in Laurell et al., 1992; *Part five 5 paper 7*, with an example shown in Figure 3).

A Brazilian research group subsequently modified the questionnaire after they used it with workers from different unions, to standardize the information and enable computer processing or add to the processes of observing and analysing the work (Facchini and Gastal, 1992; Noriega, 1995).

Figure 3: Risk map of a steel mill



Source: Laurell and Noriega (1987)

## SEE PART 5: PAPER 7

Laurell et al. (1992) describe in more detail the full process and tools for the studies implemented on workers' health using risk maps and collective questionnaires in Mexico. They also compare the information on risks, health damage and their relationships using participatory methods with that obtained from individual questionnaires.

SEE PART 5: PAPERS 11 and 12 for different examples of processes for participatory action research and the tools used for these processes.

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RS-130 p14



The processes described in this section follow similar steps of listening, systematizing experience, problematizing, drawing out evidence, analysing, acting and transforming. All shift power towards those involved. However, the way this is done varies across settings. The workers' model reflects a conflict or emancipatory model in relation to knowledge and power.

In a totally different process, inspired by Freire's critical thinking, Theatre for Development was developed in the mid-1970s in East Africa and in Botswana from a confluence of work on critical awareness and conscientization, social analysis and liberation theology. Theatre for Development uses dramas as 'codes' to facilitate analysis. Facilitators conduct 'listening surveys' in communities and prepare codes, such as pictures or songs, which reflect local conflicts and problems. Each code is then discussed and analysed with focus groups or at an open meeting, within the context of human relations, exercises that build self-esteem and motivation. Through this analysis, plans are made for action. Action provokes further reflection, discussion and analysis. Theater Delta is an example of a process that has developed from this, using interactive and participatory theatre to promote analysis, dialogue and social change in communities in many countries globally but particularly in the USA (see <http://theaterdelta.com/>). A further example of the use of these approaches in Nigeria is described in *Box 15* below.

The qualitative nature of these methods and the shift of control to communities does not make them less valid or reliable in scientific terms. It may do the opposite, as further discussed in *Part three*. For example, in 1992, the RUHSA Department of the Christian Medical College, Vellore, South India compared two approaches to wealth ranking to identify rural poor people. The first was a composite index calculated from a survey of social conditions and assets using a pretested structured schedule, administered by five experienced investigators. The second was a community classification generated through wealth ranking. The two classifications led to the same conclusions for 62% of households. For the 38% of households where there were discrepancies between the results obtained through the two methods, half were investigated by senior researchers by making home visits. They found the community classification better reflected the observed reality found in the home visits in 92% of the discrepancies they examined (Chambers, 1994).

As raised earlier, some processes triangulate participatory analysis with more positivist experimental methods. Laurell et al.(1992: *Part five paper 7*) compare information on risks, health damage and their relationships using participatory methods with that obtained from individual questionnaires. Even within a participatory research process, the homogenous group may explicitly decide to use such tools under their control. These

### Box 15: Drama as listening survey and tool for problematizing



Practitioners at Ahmadu Bello University in Northern Nigeria integrated villagers into the process of dramatization, building tentative scenarios through a 'listening survey'. Building on local performance traditions, these dramas are rehearsed in spaces where people gather. People are invited to comment on, modify and take part in the sketches. Analysis takes place not only through discussion but through the drama itself which becomes the centre of the learning experience.

By inviting people to intervene in scenarios from everyday life, they are encouraged to explore possible solutions. Spectators become actors and acting out becomes a rehearsal for action. Theatre for Development in Nigeria is increasingly used to explore health problems and their causes, for example in reproductive health. It recognizes 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 stimulates creative conflict, to facilitate reflection by those who have power as well as to empower those who lack it.

Source: Cornwall and Jewkes (1994)

decisions and the complementary application of different approaches is highly context dependent. For example, Sweden's long history of consensus politics provided a context for deliberative, inclusive forums for public participation, while its rational approach to social policy also gave prominence to expert knowledge (Bergh, 2004). Over many decades throughout the 1900s in Sweden, various forms of research reflected both perspectives.

In one study, Gardell and co-workers investigated the role of workers' control over pace and working methods and the nature and content of the job as factors in stress and ill health (Gardell, 1982). The Gardell group worked closely with local and national trade unions on action research that located knowledge and change at the level of the shopfloor. At the same time, the Swedish Trade Union Congress also performed a series of surveys between 1968 and 1980 to influence national level negotiations. They used formal questionnaires to elicit information from members and shopfloor union representatives on their experience of work environments, including on the psychosocial and ergonomic hazards identified in Gardell's work, that up to then had been poorly recognized. By doing the survey directly within the unions, the Congress could link the knowledge to union negotiations for change. The workers representatives in the unions controlled the process but they decided to use a more traditional survey process as this was seen as more likely to have an impact in national level negotiations (Loewenson,

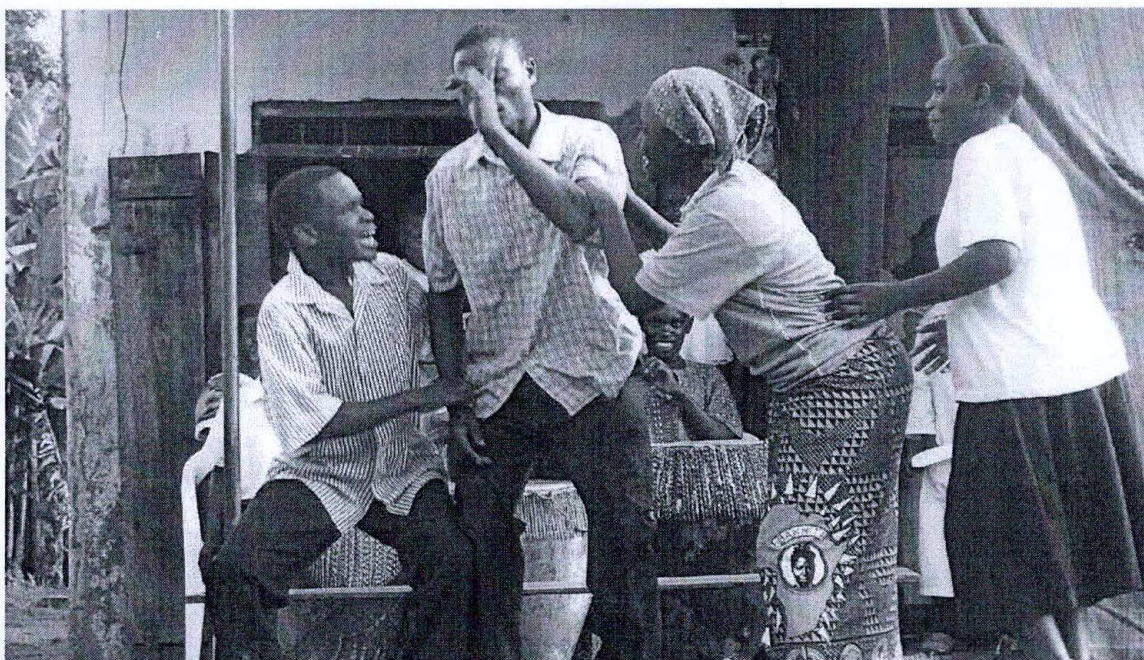
Laurell and Hogstedt, 1994; Bergh and Erlingsson, 2010).

The decision on methods needs to take into account the decision of the homogenous group on what is suitable. There is no simple toolbox or prescriptive recipe book for participatory action research. The social groups involved may select to use methods that preserve anonymity, such as in situations of high personal risk, high levels of violence and conflict or in areas where communities are sensitive about confidentiality (Bourke, 2009).

In work described by Garwick and Auger (2003: *Part five paper 8*), storytelling was identified by communities involved as the most appropriate way of gathering evidence and building trust in relationships to support reflection and action. In contrast, *Box 16* on the next page describes a different process and context where community health workers only gathered locally-generated narratives on the use of maternal health services if they felt this would not generate distrust or interfere with their roles as community-level workers.

#### SEE PART FIVE: EMPIRICAL PAPER 8

Garwick and Auger (2003) describe the cultural and social context that made narratives a chosen method in participatory action research with American Indian communities on the needs of families who care for children with chronic illnesses and disabilities. The full process and work in this long term programme is described in the paper.



© Paul Akankwasa, 2008

Community  
drama,  
Uganda



## Box 16: Using narratives in implementation research in Chicago

Outreach workers for a community-based intervention project in Chicago received training in qualitative research methodology and certification in research ethics. They used a Voice over Internet Protocol (VoIP) phone-in system to provide narrative reports about challenges faced by women they encountered in their outreach activities as well as their own experiences as outreach workers.

By collaborative agreement their role entailed systematically documenting the women's stories. These stories were seen as critical to the evaluation, as they described experiences that prevent women from accessing the health services they are entitled to. The Voice over Internet Protocol system allowed outreach workers, at their convenience, to phone in stories about the women and report their reflections about the outreach worker and researcher roles. When an outreach worker encountered a woman with a story she deemed particularly relevant to programme goals, she sought verbal consent to report the story, emphasizing that no personal identifiers would be reported. Thematic analysis was used to analyse the stories and the analysis was provided to the team involved, including the outreach workers.

*Many of the stories called in by the outreach workers mirrored risk information collected on process evaluation forms, including history of serious adverse pregnancy outcomes (e.g., preterm birth, low birth weight, and fetal and infant death) and risk factors for adverse pregnancy outcomes (e.g., extremes of age and weight and multiple unintended pregnancies). Other health data, such as information on chronic diseases, stress, depression, and domestic violence, were evident in the stories as well. In addition, the stories yielded information on a variety of health and social risks not captured by other data collection methods. Most notable were histories of incarceration, unemployment, interrupted education, unstable housing, family discord, and chemical dependency. Rather than revealing new categories of risk, data from the stories added a richness of detail that offered a much better sense of the magnitude and multiplicity of problems faced by low-income pregnant women than did the process and evaluation forms. Although data from the stories did not immediately result in programmatic changes, the issues they raised (e.g., a dire need for housing) became part of the collective discussion in the maternal and child health professional community, both in Chicago and nationally (Peacock et al. 2011: 2278).*

The outreach workers felt generally positive about their knowledge and expertise being appropriately valued. They believed the women's stories were important to tell, and to tell in detail, rather than being represented as simple check marks or a few short words on a form. However, they reported some level of discomfort in donning a 'researcher's hat' when talking with clients as this disrupted the trust needed for their normal role. It was agreed that if requesting permission to share a story was going to jeopardize an opportunity to enrol a woman in services, the workers would abandon the researcher role in the interest of meeting women's needs.

Source: Peacock et al. (2011)

## 2.4 Using new information technologies

This section explores how increasing access to information technology and the growth in visual methods and tools for networking and data collection open new possibilities for doing participatory research and for using local knowledge to produce change.

Visual and information technologies are now more diversified and widely accessible. Digital images and mapping enhance access and exchange on local

realities. Social media (blogs, tweets and others) provide ways to communicate experiences for collective analysis. Mobile phones make it possible to communicate and pool evidence across wider social networks. Mapping and crowd-sourcing technologies provide systems for citizen reporting, including in the poorest communities, such as the urban slum of Kibera in Nairobi (IDS, 2013). With cell phones doubling as cameras and video recorders and once expensive technologies now in the hands of people in low-income neighbourhoods, opportunities to use media in participatory research on health systems are growing.

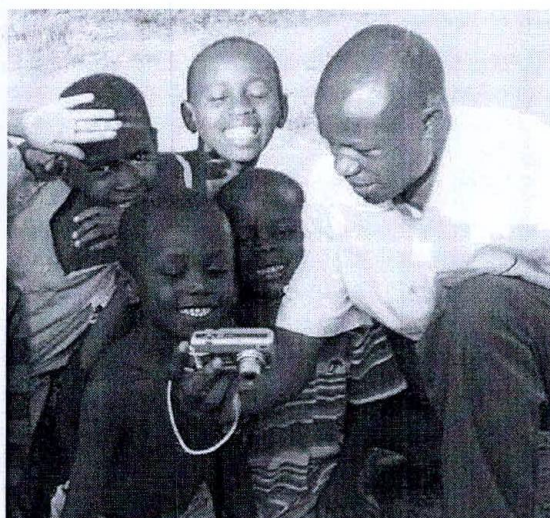
For example, in *photovoice*, photography allows people to identify, represent and have critical dialogue on processes and situations that impact on health and health systems. By building capacities in local communities to take photographs, people can record features, assets and concerns within their community or in their interaction with health systems. They can use the images to promote critical dialogue and knowledge through group discussion based on their photographs. The process provides training and capacity-building. It can enhance understanding of a community's assets and needs and facilitate changes at the policy level to help build healthy communities.

Photographs have a unique and sometimes dramatic added potential for reaching policy-makers by communicating local evidence to them (Wang, 1999; Wang et al., 2000; Catalani and Minkler, 2010). *Photovoice* projects have been used to address a broad range of health and community concerns, including asthma and diabetes, tobacco control, violence prevention, obesity and physical activity, and HIV/AIDS. They have made it possible to engage with the health needs and experiences of particular social groups in specific settings, as described in *Box 17* on the next page.

A review of *photovoice* projects by Catalani and Minkler (2010) found different levels of political, social and economic power, privilege and status among the diverse actors in the projects and concluded that a shift of power to communities was not always achieved.

Wang et al. (1998: *Part five paper 13*), who used *photovoice* with rural women in the Yunnan Women's Reproductive Health and Development Programme in China, argued that varied levels of participation were necessary to distribute the costs and benefits associated with participation ethically. Full participation from community members was central to some stages of the project, including taking pictures, selecting photographs for discussion, contextualizing and storytelling, codifying photographs, disseminating findings through community presentations, and conducting project evaluation. However, rural women were not engaged initially in conceptualizing, developing and administering the project, nor did they take part in advocating for policy change.

In contrast, Lykes et al. (2001) had been working with rural Guatemalan women for many years



Community photographer sharing images with children, Tanzania

© EQUINET, 2009

before they partnered to initiate a *photovoice* project focusing on truth and reconciliation. In this project, community control was high. Researchers served as facilitators and technical advisors to community leaders, who led every stage of the project. The high levels of participation in this project required long-term dedication to building local capacity for research and documentary photography among rural women who had little or no formal education (Catalani and Minkler, 2010).

Building on the philosophy and methodology of *photovoice*, a newer approach, *videovoice* (<http://video-voice.org>), puts video cameras in the hands of community members who similarly use this technology, combined with critical analysis of community assets and problems, to collect visual data and use it to work for changes in programmes, policies, and practices.

#### SEE PART 5: PAPERS 13 & 14

Wang et al. (1996: *Part five paper 13*) describe how photography provides a tool for women in China who previously had no voice in decision making. They can gather and communicate evidence in ways that are accessible to policy processes. Literacy is not a barrier in this method and not all the women were able to read or write. Their exhibitions were complemented by other sources of evidence, such as interviews with local anthropologists.

Young and Barrett (2001: *Part five paper 14*) used four visual techniques for participatory research with street children in Kampala to develop an understanding of their street environments and survival mechanisms and their proposals for actions to improve their lives. While the paper does not detail the actions taken, it shows the role of visual methods in making visible, realities and voice often missing from formal systems.



## Box 17: Three experiences of using photography in participatory action research with youth

### Mapping school settings in USA

The Youth Empowerment Strategies (YES!) project in West Contra Costa County, California, made *photovoice* a central part of its afterschool programme in six local schools. It engaged and trained over 120 10–12 year-olds in critical thinking, participatory research and organizing social action. As part of the curriculum, under the guidance of college student facilitator pairs, groups of five to six youths were given inexpensive cameras and taught the basics of photography, along with asset and risk mapping and other methods of assessing both the strengths and the problems in their school settings. They then discussed their pictures and collectively devised social action plans.

Of the 28 YES! groups that took place over three years, all but two developed and completed social action projects. These included a public awareness campaign about the dangers of dumping in a creek behind the school, assessing students' priority concerns and devising methods to address them, and writing to a building engineer to successfully remove a shack on campus that attracted drug users. Preliminary findings comparing participants with controls at non-YES! schools showed substantial improvements in the former in outcomes such as a sense of control, future orientation and pro-social behaviour.

Source: Minkler et al. (2012)

### Assessing inner city neighbourhoods in Scotland

In Scotland, a qualitative community-based participatory research study used *photovoice* with young people attending a youth project based in a deprived inner-city neighbourhood. Participants were given disposable cameras and took photographs of things in their neighbourhood that made them feel happy and healthy (such as parks for relaxation or efforts being made to keep areas clean) and those that made them unhappy or unhealthy (such as neglected and damaged housing, vandalism, aggressive animals). Each participant picked ten pictures and their meanings and the group used these to identify and explore aspects of their neighbourhood that had a direct impact on their mental well-being, such as uneven investment in their community or safety fears.

Analysing their discussions thematically brought out the issues most important to participants' mental well-being. Young people actively generated rich, contextualized data about their lives and neighbourhood and identified feasible actions and locally-based remedies to perceived problems in modifiable aspects of the environment that would have a beneficial effect on their mental well-being.

Source: Watson and Douglas (2012)

### Understanding factors promoting youth health in Papua New Guinea

Young people in Papua New Guinea are considered particularly vulnerable to HIV infection. Their understanding of health and HIV forms the basis of their interactions with HIV-prevention programmes, yet literature documenting their views is limited. Participatory research was conducted with 31 youths in two different settings in the highlands of the country to analyse their perceptions of factors influencing young people's health in a local context through photography. The evidence highlighted that both influential adults and the places or processes where young people and community leaders can connect were key, potentially health-promoting factors in the environments they lived in.

Source: Vaughan (2010)

A *videovoice* project in post-Katrina New Orleans' ninth ward, resulted in a powerful video shown at two large community screenings. The screenings, which attracted 200 people, raised a dialogue about race, education and other issues that reportedly motivated a community commitment to work for change.

A new local non-profit organization has since made several other videos using the information gathered and used the videos themselves to press for policy change, with thousands of hits on YouTube for clips from the videos (Catalani et al., 2012 in Minkler et al., 2012).

VideoSEWA (<http://www.videosewa.org>) is a further example of the use of video. This is a cooperative owned and run by women workers and associated with the Self-Employed Women's Association in India. Vegetable vendors, artisans and construction workers learned to produce video films and used the technology as a tool for collecting and communicating testimony, experiences and voices from women workers in the informal economy, to engage on changes in policy, including in relation to health and health care.

Madon and Sahay (2002) give the example of Jana Sahayog, a non-governmental organization based in Bangalore whose mandate is to improve the information environment of slum dwellers in the city. Recognizing that much critical information is gleaned from informal sources, such as from slum dwellers themselves, Jana Sahayog identifies and enhances traditional communication skills but also uses other media such as audiocassettes and videotapes, given the level of illiteracy in the slums. Slum dwellers are encouraged to produce audio and video clips describing their problems and requirements. The research also involved using information and communication technologies, geographical information systems and e-government applications, to build and use community-based information systems ((Madon and Sahay, 2002)).

Developments in technology have also created new possibilities for participatory mapping. In addition to photography by the community, other approaches being used include photo elicitation interviews and public participation geographical information systems (GIS). Hassan (2005) describes using such information technology to address the impact of arsenic poisoning in Bangladesh. A public participation system was developed by combining

methods for participatory rural appraisal and geographical information systems. This was used to organize social and resource evidence in the study area, bringing local community participation into planning for deep tube wells to mitigate arsenic poisoning.

In these strategies participants produce images, narratives and other qualitative data that can, through handheld global positioning system (GPS) units, be linked to specific locations. Experiential data can be integrated with spatial data (such as on crime, housing or transport) by incorporating both into a geographical information system for mapping and analysis. The result is a pooled picture of people's experience of health and place (Dennis et al., 2009).

Such participatory GIS mapping has been used by community groups to illustrate and provide powerful visual data to help address a wide range of health disparities. For example, a community in Brooklyn, New York, generated maps and successfully challenged the city's approval of a waste transfer station. The maps served as evidence in negotiations around the anticipated cumulative environmental impacts on neighbourhood residents (Minkler et al., 2012).

Google maps is an example of an accessible online tool that has also been used to design and customize interactive maps of local communities. It has unique features that help groups identify place markers, such as grocery outlets, parks and schools and then layer them so they can relate facilities to need. They can use them to compare distribution, for example, the number of grocery stores in an area against the number of liquor outlets (Catalani and Minkler, 2010).



*Community videovoice training, Nepal*

The technologies have been used in iterative processes. For example, in one such process, participants were provided with digital cameras and GPS units to take pictures of their neighbourhood, documenting routine use of community and recreation environments. In a second step, the photos became the objects of interviews in which individual and collective narratives were attached to particular images. The images were then mapped by participants as part of a neighbourhood-level GIS that included other spatial data. The mapping was 'interviewed' to produce a qualitative and quantitative survey that presented people's spatial experience of health. Visual, spatial and verbal analysis was combined to raise and reflect on issues that were amenable to local action and could be acted on locally and at higher levels (Dennis et al., 2009).

New social networking platforms also provide opportunities to share information across social groups in different geographical locations. For example the Ushahidi platform (meaning *testimony* in Swahili; <http://ushahidi.com/products/ushahidi-platform>) was initially developed after the violence of the 2008 Kenyan elections. Individuals could post and share information on irregularities in the election process and people responded through SMS or on the web. It has since been used more widely for social groups across countries to source and share information and experiences on different dimensions

of their work, environment and well-being. It is one of many internet-based resources that point to the possibilities for information technology to overcome the 'local' nature of knowledge generated in participatory action research. This works if it is used with systematic processes to link groups with shared interests (for example, airline workers, as in *Box 23, section 2.6*) and to organize collective validation.

This section presented some examples of opportunities available for enhanced community involvement in research and action and in policy advocacy through developments in technology. These new tools and methods may be more or less relevant and valid in different contexts. For example, the video from New Orleans mentioned earlier was argued to be critical for understanding life in a vibrant and enduring New Orleans neighbourhood. Such a video may, however, not be relevant in contexts where people do not want their testimony to be seen or for groups that do not want to be visible.

As discussed further in *section 3.3*, the internal validity of these approaches can and should be strengthened, including through triangulation with other sources of evidence and through methods to verify findings (collective validation) with community members (Catalani et al., 2012).

## 2.5 Reviewing, reflecting on and evaluating action

This section explores the methods and issues in evaluating the process and outcomes of participatory action research. It must be noted that the process itself integrates reflection and review; it is integral to the research and to knowledge generation. In *section 3.3* we further discuss issues of evaluating the quality of evidence in participatory action research.

Our search of the literature found no comprehensive or systematic review evaluating participatory action research as a practice. It would also be surprising to find this, given the range of contexts, actors and specific methods discussed earlier. There are examples of studies that have sought to link participatory action research to health outcomes.

One 2013 systematic review and meta-analysis of participatory learning and action with women's



Community  
photography  
in health,  
Tanzania

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groups found significant effects on health outcomes (37% and 23% difference in maternal and neonatal mortality respectively between intervention and control areas) (Prost et al., 2013). This review synthesised the results of seven trials (from South Asia and the first ever such study to be conducted in sub-Saharan Africa). Despite the encouraging results, the review pointed to a lack of attention to process and raised concerns over the potential for scale up (Victora and Barros, 2013).

In evaluating outcomes of participatory interventions, an element of caution is needed. Assessments that treat participation as an ‘intervention’ oversimplify it and linear causal paradigms are too limiting (Marston et al., 2013). As with all other areas of research, attributing change directly to specific actions or evidence is problematic, as it is also affected by wider factors, including economic, political, institutional factors outside the immediate scope of the work. The role of such external forces, the complex nature of policy making, institutional change and decision making and the competing, contested and changing relations in society mean that experimental designs that seek to identify cause and effect relationships are less suitable than methods that reflect on and seek to understand questions of ‘what worked, for whom and why?’, to inform strategies for action.

In some circumstances communities have called in an outside evaluator to address the possible

perceptions of funders or policy makers on the rigour and validity of the evaluation (Minkler et al., 2012). Even in these cases it may be more useful for them to use forms of realistic evaluation. Realistic evaluation explores how changes are produced and what is significant about the conditions in which interventions that influence outcomes take place (Tilley, 2000). This locates the work within the context of the broader environment and processes that affect participation and power.

More embedded within participatory action research itself, however, is reflection on practice and change as part of the knowledge-building process in the participatory action research spiral, as outlined in *section 2.1*.

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Rasmussen et al. (2006) evaluated an intervention, guided by participatory action research principles that was directed at traditional work environment problems in the epoxy plastic industry. It used a quasi-experimental design with before and after measurements and a comparison group with a three and a half year follow-up period. The evaluation included measures of health outcomes but also changes in social relations in the workplace. They found positive changes in the roles of employee-elected safety representatives, in employees’ attitudes to and collective understanding of safety as a shared responsibility and towards a less hierarchical management system. They also found a 66% reduction in the incidence of eczema and a 48.6% reduction in the incidence of occupational accidents.



### Box 18: Evaluating accountability work by Twaweza Tanzania

An East African non-governmental organization, Twaweza (meaning ‘we can make it happen’ in Swahili), is a ‘ten-year, citizen-centred initiative, focusing on large-scale change in East Africa’, particularly in education policy and practice. Twaweza’s theory of change uses the following model:

access to information → citizen action → state response → improved outcomes

In 2013, Twaweza commissioned an evaluation to reflect on the ‘black box’ of assumptions in the model and whether all were valid and achieved. The evaluation raised issues that have wider relevance to participatory processes, such as whether all steps and inputs for change are addressed or the risk of investing in demand-side processes (that build citizen demand) without similar support for supply-side processes (that build state capacities to deliver). The evaluation highlighted the need to carefully consider the most desirable form of participatory action and the ecosystem within which action is taking place. It called for measures to address the inertia within systems. It pointed out that both demand-side and supply-side processes may fail and that what may be needed is collective problem solving. This brings together citizens, states and others involved to broker relations, build trust and find solutions, recognizing that sometimes the most active citizens are themselves state employees and members of public trade unions.

Source: Green (2013)

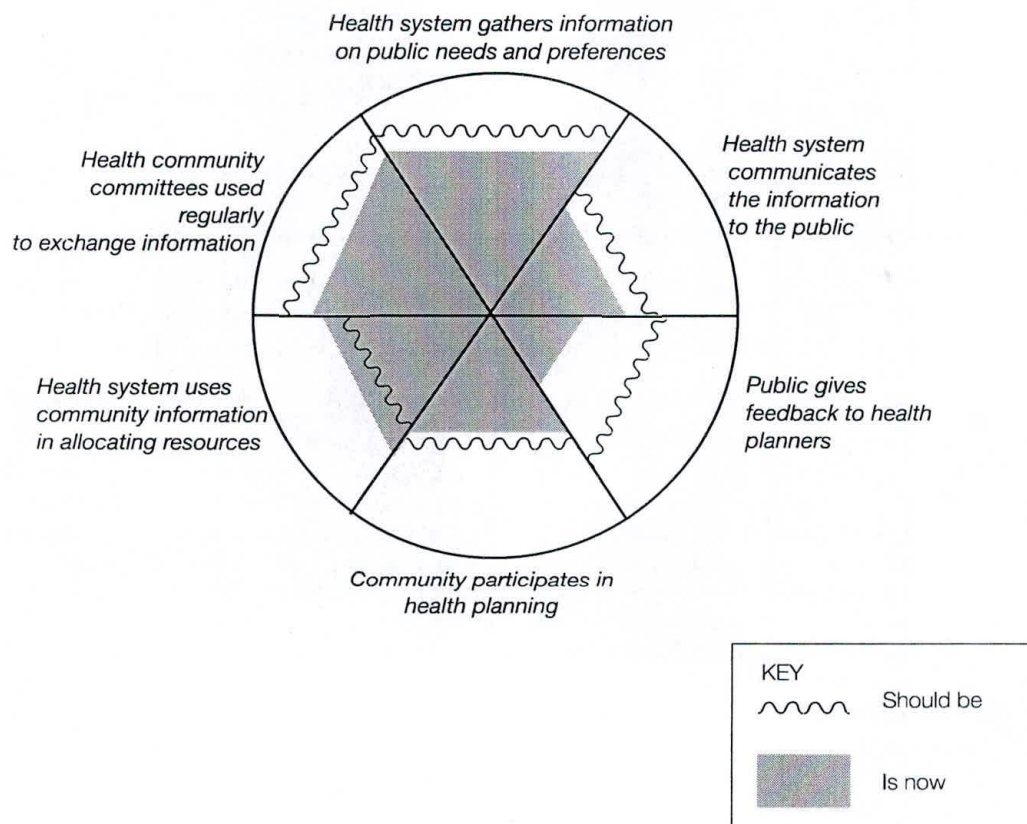


## Box 19: Using a wheel chart for participatory review

The wheel chart can be used to collectively review a range of dimensions in situations, processes or outcomes that provide a quantitative means of assessing change when repeated over time. Participants work in groups as relevant to the process. These may be social groups with different experiences of the process or outcomes, for example. They draw a blank wheel chart on flipchart paper and mark each 'spoke' on the wheel with points from 1 to 5, with 1 nearest the centre. Each segment is labelled with the feature under inquiry, such as the outcomes or process changes intended, dimensions of participation, and so on. Participants collectively assess the level of the outcome. For each segment of the wheel, they discuss the situation or outcome and decide on the level. Once they've decided, they shade the area of the segment to show this.

The wheel chart can also be used to reflect the level they intend for an outcome, or what the situation should be. This can be marked in each segment with a squiggly line (as in the diagram). The space between the two markings creates a clear visual picture of the gap between what the situation should be (squiggly line) and what it is now (shaded area). The levels may also be quantified, to give a measure of the difference. After the chart is completed it is 'interviewed'. This involves the groups discussing the differences and similarities between each of the wheel charts or, if the charts are repeated over time, the differences over time and what is driving – or blocking – the change. If the wheel chart is used to measure progress over time, the shaded area would reflect the situation at the start and future squiggly lines or new charts would document any changes.

In all cases the chart is used as a basis for discussion to explain what changes have taken place, what is causing them and what can be done about them. The ratings and interpretation of the collective group are recorded. The wheel chart has been used extensively in participatory work in the pra4equity network in EQUINET in east and southern Africa to reflect on dimensions of participation in health systems and how they have changed through participatory action research processes.



Source: Loewenson et al. (2006)



## Box 20: Lusaka progress markers and their status in 2006

What we expect to see	Done?
1 Health centre receives formats and guidelines on next year's plan	Yes
2 Health centre management committees give health centre committees and departments feedback on planning guidelines	Yes
3 Health centre and community hold planning meetings together for next year's plan	Yes
4 Participants present able to explain planning format to others	Underway
What we would like to see	
1 Agree on priority activities for next year's plan	Yes
2 Draft action plan done together with community	Underway
3 Feedback on planning through regular meetings between health workers and community members	Yes
4 Health centre committees and departments receive a quarterly financial report	No
5 Participants present able to write a plan as per format	Underway

Source: Mbwili-Muleya et al. (2008: Part five paper 6)

The methods and tools described in earlier sections, such as participatory mapping, ranking, collective questionnaires, diagrammatic tools, calendars and photography, can equally be used to review and evaluate the process. These tools help to reflect on where changes are and are not happening, whether they are in identified outcomes or in internal processes and on the voice and power of different groups in the process (see example in *Box 19*).

A further method for such collective review of progress against goals was used in Zambia by mapping the outcomes against progress markers set. This approach was adapted from the outcome mapping approach by Earl et al. (2001). As used in participatory action research, progress markers are selected at the time of identifying action plans in terms of what participants would:

- *expect* to see (usual situation);
- *like* to see (higher level or improved situation); and
- *love* to see (more ideal situation).

These progress markers are then used to monitor progress towards the desired outcomes on these actions and regular meetings are held to assess progress and discuss what obstacles need to be overcome or opportunities tapped. An example of progress markers used in work by the Lusaka District Health Management Team on the communication between health workers and communities in planning is shown in *Box 20* above.

More information on the use of the progress markers is found in the paper by Mbwili-Muleya et al. (2008: *Part five paper 6*) where ongoing review was a key element in a long-term process of system change. Further methods for participatory evaluation are also described on the Community Tool Box website (<http://ctb.ku.edu>) (Minkler et al., 2012).

The process of reviewing action needs to factor in the time dimension of the change envisaged. Some institutional or policy changes may be quick. Hence for example the local changes described in Kawakami (2006: *Part five paper 12*), Mbwili-Muleya et al. (2008: *Part five paper 6*) and Inmuong et al. (2011: *Part five paper 9*) are local system changes that were under the control of the communities and local level health workers and managers.

Many changes take place over a longer period of time and with multiple influences. This leads to approaches that embed participatory review and evaluation as a part of the institutional functioning of health systems, rather than as 'one-off' events. This was done in the institutional change described by Batista et al. in Brazil (2010: *Part five paper 15*), in the wider roll-out of the process in the health system described in Mbwili-Muleya et al. (2008: *Part five paper 6*) or as described in *section 2.7* on the information system for child health in Cape Town (Byrne and Sahay, 2007).



## Box 21: Evaluating participation in Ghana's community-based health services

Spider diagrams were used to assess participation and apply it to a Community-based Health Planning and Services (CHPS) programme in rural Ghana.

In a community conversation with a mix of service users, providers and community health committee members, those involved collectively evaluated community participation in the CHPS programme, using the spider diagram to highlight factors that sustained participation (such as recognition and use of community resources, integration with pre-existing community structures and alignment of services with community interests), and those that blocked it (including male dominance and didactic community leadership and management styles).

Source: Baatiema et al. (2013)

The level of participation and the power shifts taking place in research are dynamic phenomena that are themselves matters for review (Chung and Lounsbury, 2006). In one participatory research study, changes in both the level and the nature of participation were assessed over the course of the work. This work demonstrated how a shared understanding of participation evolves as the roles and relationships of those involved are negotiated and renegotiated. It also raised, importantly, that lack of reflection over power differentials can lead

to disempowering outcomes, even after achieving a seemingly participatory process. Failing to resolve divergent assumptions about power and purpose can lead to fissures that are difficult to overcome (Chung and Lounsbury, 2006).

There are separate processes to assess the quality of participation itself and particularly whether the intended shifts in power and control are taking place within participatory action research, as this is an inherent goal of the approach. Those involved in the process have used tools, such as those described in Mercer et al. (2008), 'Reliability-tested guidelines for assessing participatory research projects', to help periodically 'check in' on how a coalition is doing in terms of process and functioning (Minkler et al, 2012). It is, however, notoriously difficult to assess participation.

A range of participatory methods can be used, including those described earlier, except at this stage the question focuses on the quality, level or distribution of power, participation or control among different members of the group or elements of the system in the participatory action research process.

One example, described in *Box 21*, is the Ghana Community-based Health Planning and Services programme that used spider diagrams to evaluate participation. Spider diagrams could also be applied to understand the different experience of participation of different social groups, such as women, young people or marginalized men, allowing a more disaggregated analysis of who the process was working for and how (Baatiema et al. 2013).



Using a spider diagram to assess health committee roles,  
Regional meeting, Harare

## 2.6 Meta-analysis and methods for analysing

One concern in participatory action research is how far the knowledge gained can be more widely generalized. The context-specific and purposive nature of homogenous groups can limit generalization to other settings. *Section 3.4* discusses this further.

Individual methods can be scaled up and applied at a wider level. Participatory wealth ranking has, for example, been combined with other qualitative and quantitative data to increase comparability across contexts, so that local perceptions of poverty can be used in developing indicators that are comparable across communities. Chambers (2007) cites various examples demonstrating the potential for wider generalization of evidence from participatory action research (see *Box 22* on page 64).

Chambers (2007) also presents examples from the Philippines of local evidence that was used at the national level. When grass-roots health workers made their own disease maps and produced village figures at variance with official statistics, officials reportedly came to accept them as they proved more useful for planning priority actions. Participatory land holdings investigation in the Philippines reportedly led to revising figures which doubled local government takings from the land tax (Chambers, 2007).

Meta-analysis of findings from different locations where participatory action research is being done on the same area of study can also be carried out using similar processes to those used for meta-analysis of qualitative research. A review of literature on these approaches identified a range of methods used for this (see Table 6 on page 64) with selected references exemplifying the method (full references are cited in Machingura et al., 2011). Commonly, these approaches analyse the content of findings using themes or common categories and interpret comparisons across sites to draw conclusions.

This section does not go into detail on the various methods. The references cited in Table 6 give details of the methods for each approach, in terms of how they organize the information from individual sites as a basis for comparison and analysis (for example, through a structured thematic analysis, content analysis or using a constant comparative element in grounded theory) or how they compare and contrast

findings to build new combining concepts (such as in meta-ethnography).

As for all meta-analysis of qualitative evidence, difficulties arise in comparing data, for example in making assumptions about common determinants of outcomes in comparisons across different contexts and environments and in determining common categories or themes across different settings (Dixon-Woods et al., 2007). Thus in carrying out meta-analysis of participatory action research it is important to provide evidence on individual contexts, to ensure that the concepts used are transferable across sites and to retain information on outliers and differences as well as present common trends.

One way of generating knowledge across sites is for the work to be cross border by design. While many studies are applied at local, district or national levels, there are a few examples of research that is applied at the international level in health and that explicitly seeks to integrate the key principles of participatory action research. One factor that has limited such cross border health or health system research has been identifying a 'homogenous group' at that level, that is one with shared conditions and a shared organizing framework.

An interesting example providing a basis for this is the case of aviation sector workers and their international trade union, as shown in *Box 23*. This unique study was enabled by the presence of an international trade union organizing a group of workers with relatively common work experience.

While most research on health systems and policy generally and participatory action research in this field specifically is conducted at national or sub-national levels, some factors are likely to drive more cross border participatory action research. One factor is the globalization-driven emergence of shared determinants across social groups, with public health risk or experience common across countries. The convergence of health system policies and approaches through global policy setting may also lead to people across countries identifying shared realities in their experience of health systems or in the policy reforms taking place in health systems. This is particularly so if organizations enable this identification of shared experience. Examples of these include social movements of people living with HIV or the international union movement for the aviation workers described in *Box 23* on page 65.



## Box 22: Development of a participatory poverty index in China

Work was done in China to develop a participatory poverty index (PPI) in 2000/01, based on eight common indicators representing people's ranking of their priorities and their assessment of their levels of deprivation based on those priorities.

Community discussions were facilitated to develop a consensus relevant to the community as a whole and to assign weights to each indicator. To ensure comparability across communities, the weights used in each setting are summed to unity (the relative not absolute amounts are used). A composite PPI was calculated for each community, allowing a comparison of the relative perceived deprivation between communities. The higher the PPI, the greater the incidence of poverty in the village and the deeper the experience of poverty. The methodology was tested and proved robust and is reported to be widely used in village planning.

Source: Chambers (2007)

**Table 6: Methods for synthesis of qualitative information**

Synthesis method	Basic assumptions and methods	References
Meta-narrative synthesis	Synthesizes a number of qualitative studies by summarizing key issues from individual sites. The method seeks to interpret rather than aggregate the information from each site.	Greenhalgh et al., 2005; Popay et al., 2006
Critical interpretive synthesis	Presents and interprets evidence from individual units or sites of study as a basis for grouped analysis. The research team interprets the evidence to build new concepts and theories.	Dixon-Woods et al., 2007
Meta-ethnography	Involves the selection, comparison and analysis of studies across sites, comparing findings across sites to identify key concepts emerging through interpretation of similar and contrasting findings.	Britten et al., 2002; Harden et al., 2004; Sandelowski and Barosso, 2007
Grounded formal theory/grounded theory	Uses a constant comparative element to define emergent concepts based on common issues from research sites. Involves an iterative process to move from evidence grounded in specific contexts towards a generic theory with a broader application.	Glaser and Strauss, 1967; Strauss and Corbin, 1998; Pope et al., 2007
Thematic synthesis	Identifies major or recurrent themes and summarizes findings under thematic headings. This offers a structured way of dealing with the evidence in each theme.	Harden et al., 2004; Thomas and Harden, 2008
Textual narrative synthesis	Describes findings across existing research reports using content analysis approaches, where frequency of mention of content is used to determine the strength of the evidence.	Lucas et al., 2007
Qualitative synthesis/meta-synthesis/meta-study	Combines findings from different studies using different qualitative approaches through use of common categories. Combines and compares different types of information within those categories but the variation in study characteristics and methods may weaken generalizations.	Paterson et al., 2001; Thorne et al., 2004; Sandelowski and Barosso, 2007
Content analysis	Categorizes data into themes and counts their frequency in an organized technique.	Hodson, 1999
Case survey	Translates recordings and information from qualitative research using common categories.	Yin, 1994
Qualitative comparative analysis	Summarizes and compares qualitative evidence from individual research studies within common categories.	Ragin, 1987

Source: Machingura et al. (2011)



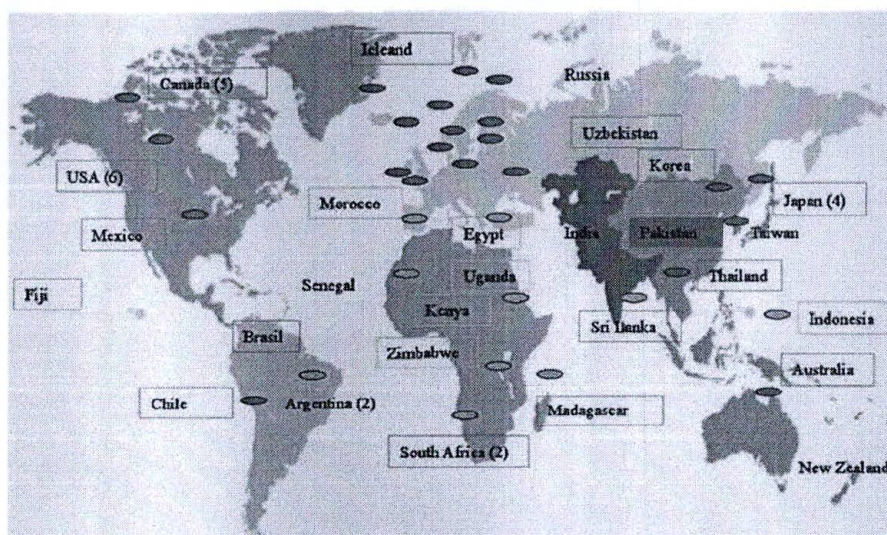
### Box 23: Stressed and fatigued on the ground and in the sky: a global study of aviation worker conditions in 116 countries

At the 2006 International Civil Aviation Congress, delegates identified stress and fatigue as the common priority issue among the International Transport-workers Federation's (ITF) three main aviation sector industrial groups: air traffic service workers, cabin crew and ground staff. Congress delegates from all regions expressed a strong sense that a serious increase in stress and fatigue had occurred since 2001, affecting members from all three occupational groups. They suspected that this increase was largely triggered by the events and aftermath of 11 September 2001. The ITF was asked to try to identify the main factors contributing to what appeared to be a pandemic of increased stress and fatigue, and to create policy action based on the information obtained. Participatory action research methods were used to explore what happened to civil aviation workers around the world between 2000 and 2007, in terms of their conditions and their health.

Every aspect of the study was developed and carried out jointly between the ITF and the researchers. The team consisted of twelve people, working in six different countries and included four members from the civil aviation section of the ITF. The methodology enabled the team to develop collective knowledge of the causes of emotional stress and fatigue and their impacts on aviation workers. The ITF gathered structured information from workers and testimonies from union representatives from all the global affiliates in 116 countries in all regions. By virtue of being both union representatives and civil aviation workers, the union affiliates were also considered the best placed and most knowledgeable to develop policy recommendations and priorities from the study.

Evidence gathered was triangulated with information from the literature, studies previously undertaken on stress and fatigue in civil aviation workers and from the union's civil aviation occupational health and safety working group meetings. The findings revealed a steady decline in conditions faced by the workers in all three occupational groups and in all regions between 2000 and 2007. Stress and fatigue among civil aviation workers had become global in nature in the period and had worsened progressively since 2000. The study revealed that work-induced musculo-skeletal disorders were widespread and resulted in disability, lost work time and reduced job performance.

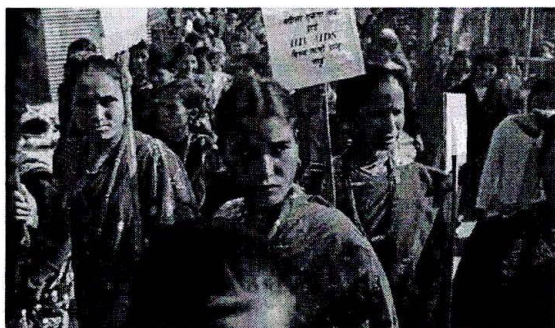
A range of changes in work-related conditions were identified as associated with these health outcomes. More frequent use of temporary and contract labour in 2007 compared to 2000 was associated with a higher level of reported overall work stress among all three groups of workers. Many unions are using the study findings at the national level, while international minimum standards were followed up on by the ITF at international levels. The study emphasized the need for close and active union collaboration, strong organizing efforts, solidarity and campaigning at local, national, international, and regulatory levels.



105 respondents  
from 54  
countries  
(shown by  
ovals) returned  
completed  
questionnaires

Source: Roszkam et al. (2009); For more detailed information, see:  
[http://unhealthywork.org/wp-content/uploads/Published\\_ITF\\_Stress\\_and\\_Fatigue\\_Study\\_Report-1.pdf](http://unhealthywork.org/wp-content/uploads/Published_ITF_Stress_and_Fatigue_Study_Report-1.pdf)

A World  
AIDS Day  
procession,  
Nepal



The widening of information technology has enabled networking and communication across groups with common perceived situations or interests. It has generated community-led information flows into cross border social movements. For example, this has occurred with activists working on specific health risks, such as smoking, breastmilk substitutes or marketing of processed foods or on health system issues such as health worker migration or equity in access to medicines. In the last century, changes in the organization of economic and social processes, and contradictions between social groups within countries, were associated with new trends in and approaches to participatory action research. The current century offers more opportunities for this.

## 2.7 Institutionalizing participatory action research

This section discusses how participatory action research principles, processes and methods, described in Part two, have been used in the institutional practice of health systems. As a complementary section, *section 4.2* discusses the use of participatory action research in policy making.

By its nature, participatory action research assumes that health systems seek to:

- deliver on the highest attainable standard of health and on health care as a human right, with implications for: the content of that right; the ability and power of those entitled to claim it; and the organization and capability of systems to deliver it;
- be people-centred and acknowledge the role of various actors and the relations between them as key factors in delivering on the right to health care and to health;
- promote well-being and, in line with primary health care approaches, improve population health and provide personal care and rehabilitation;
- expose and prevent health damage caused by living, working and socioeconomic conditions and patterns, from local to global level, and facilitate action by and with other sectors;
- address inequities and redistribute resources towards those with highest health need, ensuring uptake and universal access and coverage, understanding that doing so demands action to confront wider social inequalities; and
- build knowledge, capacities, resources and the social and political support and leadership for these roles and actions.

Participatory action research has been used to build knowledge on various aspects of the way health systems deliver on these roles. By recognizing power (and thus struggle) as an integral dimension of knowledge and systems, it has often been used



### Box 24: Using participatory action research in orienting health services to needs of elderly people in rural China

Liu et al. (2006) used participatory action research methods with disadvantaged elderly people in rural China. The aim was to identify their perceptions of their health needs and the barriers they faced in accessing services and to address these needs, including by promoting health services.

Various service providers discussed the evidence from the elderly people with them and consensus was reached that comprehensive cooperation was needed to provide support and address the mix of social, economic and environmental factors affecting health in this community.

The county government office, older people's affairs office and village leaders developed a co-ordinated approach, from measures to improve health services, such as physical screening of older adults, to wider services such as making land available for elderly people.

Source: Liu et al. (2006)



### Box 25: Participatory pharmacovigilance in Uganda

Traditionally, post-marketing pharmacovigilance (drug safety) relies on clinicians reporting adverse events. In many settings, a large proportion of treatments may be provided by non-clinicians or lower-level health workers who find adverse event forms challenging to complete, limiting the effectiveness of the process.

In participatory research in Uganda, therefore, efforts were made to develop user-friendly adverse event report forms to capture information on events associated with anti-malarial medicines. Following a situation analysis, community medicine distributors and health workers were directly involved in developing and testing a reporting form based on the experiences and needs of users and taking their visual perceptions into account.

The process resulted in a form that included a pictorial storyboard to communicate the rationale for the information needed and to facilitate rapport between the reporter and the respondent, together with a diary format to record the drug administration and event details in chronological relation to each other.

Successive rounds of pretesting involving community medicine distributors and health workers were used to refine the form, with the final round showing over 80% of forms completed correctly by potential end users. The participatory approach was seen as effective for developing forms that are intuitive for reporters, and motivating for respondents.

*Source: Davies et al. (2012)*

to address issues of equity and injustice in health systems, such as in differential exposures to risk or inequitable access to health care services, and thus to raise the profile of vulnerable groups in health.

Other research approaches have also provided perspectives on issues of equity and social justice in health systems. Feminist research has contributed to an understanding of gender and inequality in health systems and has also highlighted the importance of 'exploring feeling and experience as sources of knowledge and as guides to analysis and action' (Martin, 1996:84). Hence, for example, hunger as a phenomenon that is experienced is shown to differ from hunger examined as a technical issue. In the former, people's feelings and their interpretations of hunger provide evidence on social phenomena that the numbers often miss. Research that analysed songs sung by Malawian women during a hunger crisis thus revealed the particular suffering women and children experienced during the famine. This was as a result of men leaving home to find food and not returning because they settled with other women in areas where food was plentiful (Martin, 1996).

Participatory action research has been used to understand the interface between the health system and communities or specific social groups and to build knowledge and action around social and structural determinants of health. However, as described in this section, this is not exclusively the

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Borgia et al. (2012) describe the processes of creating the National Integrated Health System in Uruguay that attempted to reverse the existing fragmentation and inequity in access, opportunity and quality of health care. Implementation prioritized comprehensive providers of services at the three levels of health care. Participatory action research approaches were used for communities and their organizations to contribute to this organizational development, with face to face dialogue between health authorities and the population in geographically remote communities. The process connected people with their peers and facilitated the exchange and horizontal cooperation needed to develop the system.

case and participatory action research approaches have been integrated in national processes and in common settings in different states or countries.

In delivering on rights to health and health care, health systems need to overcome the many ways communities are marginalized from care. This is due to various barriers of availability, relevance, accessibility and acceptability as well as the way people experience the system when they use it. Participatory action research methods can play a role in exposing these barriers and areas of marginalization and can facilitate voice and agency for those affected in the process of acting on these conditions as described in *Box 24*, for example, in China.

In another example, given the lifestyle of the nomadic Somali community, little was known about their perceptions of preventive healthcare services or their health needs in general (Maalim, 2006: *Part five paper 10*). The best source of information regarding these matters is the community itself. In participatory research in late 1999, Somali nomads explored how healthcare services could be improved to suit their nomadic lifestyle and social norms and interactions. They described their seasonal movements diagrammatically and, by reflecting on the patterns in relation to the system, proposed ways to provide better mobile and outreach services. They identified how health workers could use the intricate information network of the community to build relationships and to better understand and respond to the community and its health problems (Maalim, 2006: *Part five paper 10*).

People-centred health systems imply that participation and relations in health systems, and the role of people's health literacy, experience, actions and decision-making power are centrally addressed in designing and planning health services. Participatory action research has been used to build informed decision making and to involve users, including in areas where service uptake is poor. This reader cites examples in different sections: in organizing community mental health services in Othieno et al. (2009: *Part five, paper 5*); in social participation in planning and budgeting in Mbwili-Muleya et al. (2009: *Part five, paper 6*); in designing service outreach to respond to the practices of nomadic people in Maalim (2006: *Part five, paper 10*); or in reorganizing the rural health system in Uruguay in Borgia et al. (2012: *Part five paper 17*).

While much scientific research has focused on identifying new interventions for prevention and treatment, there is increasing attention to a deficit of research on implementation. This would explain why knowledge of 'what works' in theory is not being applied or does not reach people in need, a key area of health policy and systems research.

Adverse events in health service delivery have an important feedback loop in that failures and deficits in intervention can lead to new risks such as drug resistance, as is the case with antimalarials and many antibiotics. Any mass roll-out of interventions should thus continue to be monitored for their use and safety. Participatory action research approaches

have been institutionalized as part of the surveillance of new interventions as exemplified in *Box 25*.

Mbwili-Muleya et al. (2009: *Part five paper 6*) discuss how participatory action research approaches build community roles in budgeting at the primary care level. There is less evidence, however, on the use of participatory action research in addressing inequities and redistributing resources towards those with highest health need through improved allocation to primary care levels.

In the USA, neighbourhood action teams using participatory action research approaches were included in local planning, with the input from residents leading to: changes in bus services; better access to education and employment; installation of speed bumps; improved lighting; youth activities to reduce safety risks; the removal of a billboard tobacco advertisement; community clean-ups; more frequent garbage collection; and more police patrols. Some residents have become involved in city and regional decision-making and the participatory processes for wider community links have reportedly been sustained (Minkler et al., 2012).

Approaches such as community monitoring thus complement formal systems in organizing community-based evidence and bringing it into decision making, such as for transparency and accountability of the organization and delivery of services, as discussed in *section 1.2*. However, participatory action research can also be used in framing the routine information systems themselves, given their use in resource allocation and decision making in health systems. They also need to be understood as socially constructed and value-laden. The work by Byrne and Sahay (2007), outlined in *Box 26* on the next page, exemplifies this. It shows how data collected in information systems can be transformed into knowledge and action by integrating the interpretation and meaning people assign to them. This influences the use and interpretation of the information system and its further development.

*Section 4.2* discusses further examples of the use of evidence from participatory action research in policy. The next section explores issues to be addressed in applying the methods, including the ethical standards to be maintained in implementing this kind of research.



## Box 26: Building a community-based child health information system

The process of developing a community-based child health information system in Cape Town, South Africa in 2002/3 involved those responsible for children's well-being in designing and developing the system. The project included community members and had to recognize that the community was made up of diverse social groups with different and sometimes conflicting interests.

Through local-level workshops, community interviews and focus group discussions, community-level researchers and facilitators addressed the question of what people responsible for children's well-being and other community members regarded as needs to be fulfilled and goals to be achieved by systems supporting child health. Local people acted as facilitators during the discussions and interviews with community health workers, community field facilitators and orphan group 'mothers'.

In the initial stages, because of differences in status and roles within the community, groups comprising, for example, mothers, children, councillors and facilitators met separately to discuss what they wanted for children. These meetings were conducted in the local language and near homes or workplaces. Representatives from the various groups met jointly to share findings and to discuss the way forward.

One element arising out of these discussions was the need to measure child health status in more holistic terms, beyond physical well-being alone. Conditions for well-being and risk were not viewed as isolated factors but as interwoven in a socially, politically and culturally complex situation. Initial meetings developed a local term for indicators, '*izinkomba*' and explored broad areas of measurement rather than precise formulations. Community members did not want to put numbers to childhood vulnerability but to find measures to enable them to track changes and identify the actions needed when a child was falling into risk.

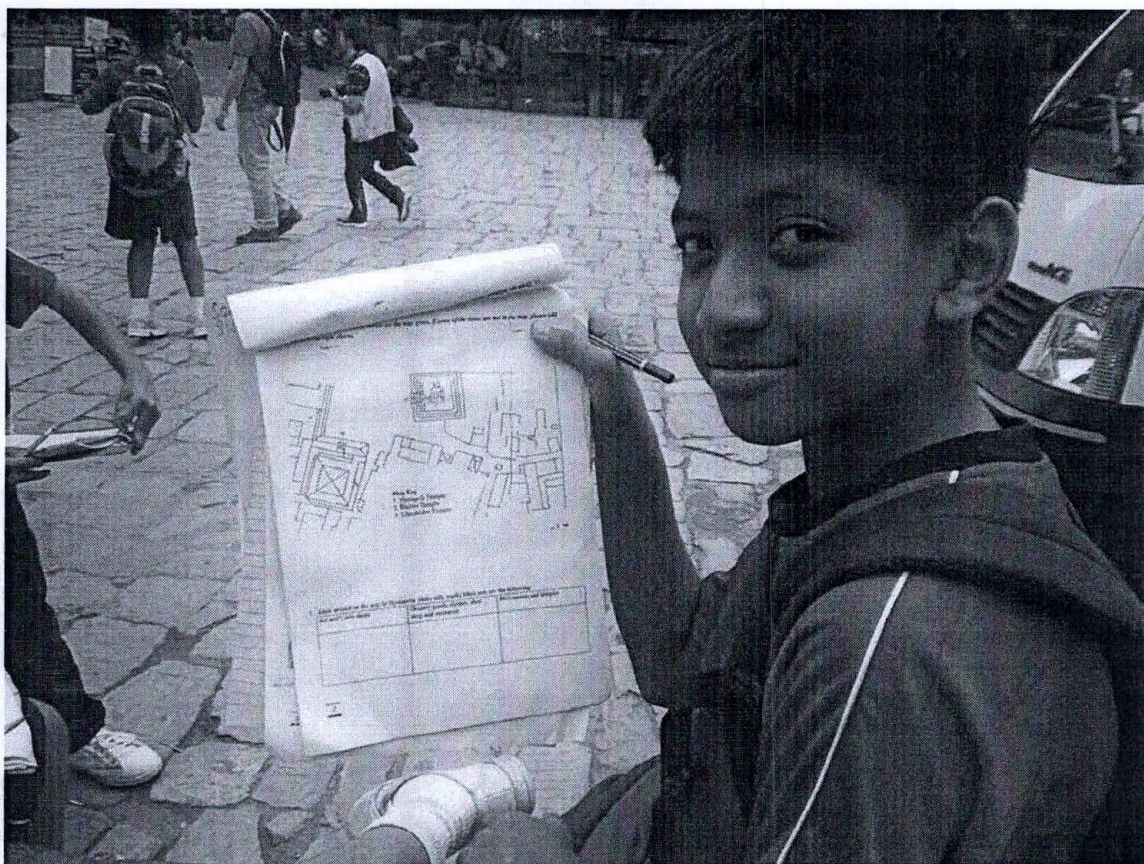
From focus group discussions and interviews, various *izinkomba* for well-being and risk were suggested and grouped into common areas or themes. Working sessions with representatives from the district health management team, the project and community members, as well as discussions with community health workers and facilitators, helped to refine these *izinkomba* and to decide who would collect them and how often they would be collected. Not all indicators identified were quantifiable, which was different from the predominant focus on quantitative indicators in previous health information system design.

The system, built upon the traditions and culture in practice, emerged as primarily paper-based and orally communicated. It added new areas of information, such as community monitoring of the context in which a child grows up, to draw attention to areas where intervention was needed to prevent illness. It also built direct links between community members and the health facility information system in making decisions concerning children's living and socioeconomic conditions and care. Community members were viewed as part of the data and information flow and necessary to support action.

Using an observation form, the community health worker assesses and registers the risk or well-being of the child at monthly household visits and discusses the situation with the caregiver present. Advice is given immediately, possible solutions are identified, referrals made and, if necessary, assistance is provided in household decisions. The community field facilitator compiles data gleaned by individual community health workers and follows an 'assess, analyse and act' process to discuss the data and share experiences on a monthly basis.

The aggregated data (at village level) are presented to the community at quarterly village health days which are chaired by the community health committee and organized by the community health workers and facilitators. Parents (mainly mothers and grandmothers), schoolchildren and district staff attend the meeting. Feedback from the aggregated data is given through song, dance, poetry, role-play and bar graphs. The compiled community data (for all villages in the municipality) are sent to the district health information officer who includes this aggregated municipality data in monthly feedback reports to the health facilities and to the district programme staff. This means that they are also shared with other programmes at district and higher levels and with the local government. The districts are then asked to give feedback questions to those who submitted the data, to facilitate reflection and analysis.

Source: Byrne and Sahay (2007)



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## Part three

# Issues & challenges

*Part three cover page photo:  
GIS training, Nepal*



## Part three

# Issues & challenges

*If you are neutral in situations of injustice, you have chosen the side of the oppressor. If an elephant has its foot on the tail of a mouse and you say that you are neutral, the mouse will not appreciate your neutrality.*

*Reverend Desmond Tutu*

As with other research paradigms, participatory action research has limitations and challenges, both in design and application. While reliability, rigour and validity are key concerns, the methods used to achieve these are different and often not well understood. The core method for knowledge production – various forms of collective review, analysis and validation of evidence by homogenous groups or groups that share the same conditions – is often not rigorously applied. Depending on the context and design, the findings are often specific to particular social groups and sites, and the methods for meta-analysis across participatory action research sites are not as well developed, affecting the scale and generalizability of findings (Loewenson et al., 2011).

*Part three* discusses these issues in participatory action research in relation to: the selection of groups; the quality, reliability and validity of the knowledge built; and the methods for generalizing the knowledge.

Researchers in participatory action research bring more than method to their work. They are often committed to radically reconceptualized notions in relation to objectivity and regard research as a vehicle for change. This change is often to address injustices in health and inequities in health care and to make the shifts in power needed for people to control their lives. As noted in *Part one*, these outcomes demand time to build trust. The methods are not only dependent on their design but also on the facilitation skills used in applying them.

As noted earlier, issues of participation and the shift in power so central to this kind of research cannot simply be dichotomised into 'good' or 'bad'. The research practice itself needs to be situated in the context and dynamics of participation, its quality and outcomes to understand how and why participation is achieved in particular environments (Cornwall, 2008). As with other research approaches, ethical principles apply in participatory action research. These principles are located within the context of research that involves active participation, also raising issues for implementation. These principles and issues and how they are addressed are discussed in this part of the reader.

This section discusses procedural issues that have to be addressed to ensure ethical practice in this approach. Those implementing the research need to understand and plan for the environment and capacities that affect ethical practice, including those relating to communities, researchers, policy contexts and resources. A shift in power and control to the community involved implies a level of organization and cohesion to co-initiate and assume control, as for example existed among workers and trade unions. If this does not exist there is a danger that elites will capture control or that control will be held by the researcher. The paper by Mbwilli-Muleya et al. (2008: *Part five paper 6*) shows how this growth in social control and power may take place over time and over several rounds of the process. For researchers or their institutions, beyond the orientation and capacities discussed in *section 1.5*, ethical practice means being committed to

this shift in control and the relationship needed to achieve it and a willingness to be clear about mutual accountabilities. Researchers and the social groups involved need the capacity to ensure and review ethical practice, discussed later in this section. How participatory action research processes interact with the interests and power relations in policy and funding processes also need to be engaged, as discussed later in *section 3.5* on logistics and in *section 4.2* on using participatory action research in policy.

In *Part three*, we also discuss the individual and institutional challenges in participatory action research. Control over knowledge generation by the community and iterative steps of reflection, analysis and action that build a dialectic between theory and practice go against the grain of established academic procedures, funding expectations and individualized reward structures that devalue cooperative work (Israel et al., 2005). The wealth of work cited and presented in this reader, including in the boxes and papers in *Part five*, suggests that the perceived benefits from the participatory action research process have, in many situations, outweighed these challenges.

### 3.1 Ethics in participatory action research

This section discusses ethical issues in implementing participatory action research and how to address them, given that the central feature of this research is transferring power to those affected in generating and acting on knowledge.

As with other forms of research, participatory action research is subject to ethical review and should meet legal and ethical standards. It is thus important to develop, reflect on and set agreed procedures and principles to achieve this and to evaluate ethical matters that may affect all those involved. These procedures relate to the norms and rules that should apply in social dealings among the participants, affecting how evidence is collected, documented,

interpreted and used to avoid harm to participants. These include norms relating to protecting privacy, as well as defining the roles of facilitators from outside the community and the roles of and demands on those within (Bergold and Thomas, 2012).

Numerous guidelines on the ethics of research involving human participants exist internationally including: the Nuremberg Code (1996), the Declaration of Helsinki (World Medical Association, 2000) and the Belmont Report from 1979 (USA Department of Human and Health Services, 1979). Until recently, ethical codes concerned individuals primarily as passive subjects of research. However the harms and benefits of active participation in research also need to be recognized and ethically managed in participatory action research.

This includes ethical issues that may not be identified by institutional research or research ethics board processes. An inherent element of participatory action research is that power is transferred to the community. It is thus unethical to claim a process is participatory if all power and control is vested in actors outside the community, whether academics, funders or others (Smith and Blumenthal, 2012; Khanlou and Peter, 2005: *Part five paper 20*). Such power shifts may generate conflict from those with existing vested interests. Within the community, those participating comprise different subgroups, who have different values, histories and power. All those involved need to identify and understand the power dynamics and work towards the intended changes in the balance of power, not as a 'pre-research' external review but as an ongoing matter for discussion and review.

Various possible harms and benefits have been identified in participatory action research. Some, such as bias in inclusion, are also found in other forms of research. Community level risks and benefits may also be different from individual risks and benefits (McDonald, 2012). These risks include:

- 1 *Tensions between those more directly involved in the issue and those less directly involved in the issue and their relative power in the process.* Power imbalances may be between outside research facilitators and those inside the specific community or between different groups within the community. This is particularly important when there is a risk of exploitation or stigmatizing exposure, especially among marginalized and vulnerable people who may be subject to social labelling and discrimination;

#### SEE PART 5: PAPER 20

Khanlou and Peter (2005) address the distinctive nature of participatory action research in relation to requirements for ethical review. Researchers and members of Research Ethics Boards could benefit from an increased understanding of the array of ethical concerns and the guidelines that have been developed to address them.

- 2 *Bias in who represents communities.* As a whole, communities are not homogenous, even if the specific groups involved in the research share common conditions, as noted earlier. Some vulnerable groups, such as illegal migrants who may be formally excluded as beneficiaries of systems, may also be excluded from or poorly represented in the research process. Given that participation will be selective in larger communities, participants may become alienated from their wider community through association with the project, unless there are bridging mechanisms for communication with the wider community;
- 3 *Tensions over whose interests are driving the process,* including in relation to whether the process is captured for narrow or individual political agendas and interests;
- 4 *Managing privacy and protecting information that communities or individuals do not want widely disclosed* in the context of collective processes. This could be due to the content of the issue (such as criminalized behaviours), the nature of the group (such as undocumented migrants) or the inadvertent exposure of strategies used by marginalized groups in accessing health resources or services;
- 5 *Tensions over how the evidence and analysis is documented and reported,* and whether sections of the community or the community as a whole are excluded in this part of the process;
- 6 *How unfavourable or negative information will be managed,* so it is not buried;
- 7 *Social harms,* such as a marginal group becoming more aware of oppression and so more stressed and unhappy or the use of insensitive or inappropriate methods that may increase risks for both the social group involved and for the researcher; and
- 8 *Risks from participating in the action phase.* This may arise due to controversial or unsustainable interventions or to communities carrying too much responsibility. It may be a consequence of challenging powerful and entrenched interests. In hostile environments, challenging established power structures may unleash brutal repression on those taking action (Cornwall and Jewkes, 1995; Emanuel et al., 2004; Khanlou and Peter, 2005; Minkler, 2005; Wallerstein and Duran, 2006; Koch and Kralik, 2006; Campbell-Page and Shaw-Ridley, 2013; Puffer et al., 2013).

As noted and discussed earlier, not all these tensions can be dealt with through procedures. Addressing these issues calls for a broader set of environments, capacities and relationships and for periodic strategic reviews within the research process.

The cyclical process used in participatory action research can also present difficulties both for those proposing the studies and for ethical review processes. It would be antithetical to the research principles for researchers to propose methods for cycles that depend on how communities take the process forward. Hence while the initial methods may be agreed, having to seek ethics approval for each cycle of the research process can prove onerous.

One option for this is to develop guidelines and procedures that apply as local, jointly negotiated, ethical codes or agreements. These guidelines ensure that leadership, power and decision making are shared in the various stages from design to dissemination and should:

- identify the ethical and political issues;
- reflect local culture, needs and interests; and
- maximize close collaboration between the researcher and community partners.

Those involved disclose their interests and any conflicts of interest at the outset. Everyone needs to agree on:

- their roles and responsibilities;
  - the desired outcomes of the research;
  - the measures of validity;
  - control over the use of data and funding; and
  - the channels to disseminate findings
- (Macaulay et al., 2001).

Examples of ethical principles that could be applied in participatory action research are the 1979 Belmont Report for ethical research, ethical frameworks for community-based participatory research (Emanuel et al., 2004) and ethical principles developed by the Association of Canadian Universities for Northern Studies (ACUNS) (1997) and by Durham University (2012). They can be included in a memorandum of understanding as an ethical compact between those involved in all stages of the participatory action research process. The ethical principles are compiled from the various sources and listed in Box 27 on pages 76–77.



## Box 27: Ethical principles for participatory action research

Those involved in the participatory action research will:

- 1 Abide by any local laws, regulations or protocols that may be in place;
- 2 Take culture and cross-cultural contexts into account, disclose interests of all involved and encourage and enable people from a range of backgrounds and identities to lead, design and take part in the research, actively include people whose voices are often ignored;
- 3 Challenge discriminatory and oppressive attitudes and behaviours and ensure that information, venues, language and formats for meetings are accessible to all;
- 4 Clearly identify the basis for participant involvement and the benefit from participation, given the articulated purposes, and make clear the nature of involvement in any reporting (referred to as fair selection in some reviews);
- 5 Provide access to prior information relevant to the work and issue;
- 6 Ensure mutual respect for the language, traditions, values, standards and voice of all groups and negotiate with political and spiritual leaders in the community to obtain their input and approval for the proposed research;
- 7 Ensure informed consent, without undue pressure. Participatory involvement of communities makes it more likely that consent will be truly informed but the shift in subject-object distinction makes it unclear who obtains and who gives the consent. Those initiating the participatory action research should thus involve the wider homogenous group in the consenting process which should explain the potentially beneficial and harmful effects of the research, clarify the financing support and respond sensitively to the lived fears and concerns of all participants, especially vulnerable ones such as undocumented immigrants;
- 8 Respect the autonomy, privacy, dignity, knowledge and experience of the people involved. If people are going to be identified and individual confidentiality cannot be guaranteed, then ensure people are informed of the possible consequences of this before becoming involved in the research;
- 9 Agree on roles and responsibilities, including that of the researcher or facilitators;
- 10 Encourage and enable all participants to contribute meaningfully to decision-making and other aspects of the research process according to skill, interest and collective need, with a commitment to acknowledge and discuss differences in the status and power of research participants;
- 11 Work for agreed visions of how to share knowledge and power more equitably and to promote social change and social justice; and recognize and work with conflicting rights and interests expressed by different sections of communities or by different communities;
- 12 Work towards sharing power more equally and using methods that build on, share and develop different skills and expertise, and that promote shared learning;
- 13 Be open to challenge and change and be prepared to work with conflict;
- 14 Ensure equitable benefits to participants in return for their contribution and resources (referred to as favourable risk-benefit ratio in some reviews);
- 15 Engage in debates about what counts as 'positive' change, valuing learning and other social benefits as an outcome, and be open to the possibility of not knowing in advance what making a 'positive difference' might mean;
- 16 Use visual media in discussing and planning ethical principles and procedures at the onset, including for informed consent procedures and for participatory and inclusive editing practices;

- 17 Ensure built-in mechanisms and procedures for how unflattering results will be dealt with;
- 18 Ensure that roles and remuneration of all frontline staff and volunteers involved are addressed from the outset and reviewed over time;
- 19 Enable capacity exchanges and information sharing throughout the process and across actors;
- 20 Ensure opportunities to hold or suspend the work if social groups involved require it and to allow people to withdraw at any point;
- 21 Ensure that interventions and actions are maximally beneficial and sustainable, with fair selection of beneficiaries;
- 22 Develop agreements about the control of evidence and the ownership and publication of findings, including how reports will present the ethical code followed and credit those involved and what language(s) it will be in so that the community can keep it and understand it;
- 23 Ensure publications include dissenting views if those involved cannot agree on the interpretation;
- 24 Ensure that the principles are understood, agreed upon, respected, implemented and monitored by all involved as an inherent part of the participatory action research process.

Source: ACUNS (1997); Emanuel et al. (2004); Khanlou and Peter (2005); Minkler (2005); Koch and Kralik (2006); Durham University (2012); Angwenyi et al. (2013); and authors modified from Puffer et al. (2013)

These ethical codes or principles have been formalized in some settings, with mechanisms to oversee their implementation. Universities and indigenous organizations and communities in Canada and Australia have jointly developed ethical guidelines and checklists for participatory action research covering all four phases of research – design, implementation, analysis and dissemination – clarifying the principles and obligations (Macaulay et al., 2001). In Toronto, Travers and Flicker pioneered guidelines for equitable partnership and community capacity building in urban health research (Minkler, 2005).

To address these and other sources of insider–outsider tensions in work with indigenous communities in both urban and rural areas, researchers in New Zealand, Australia, the USA and Canada have worked with their community partners to develop ethical guidelines for their collaborative work (Minkler, 2005). The Navajo Nation Institutional Review Board, for example, provides an example of a sophisticated body that approves (or disapproves) all research being conducted with Navajo participants. All research within the Navajo community must: seek resolutions of support from local Navajo Nation chapters; provide plans for using the evidence to the benefit of tribal members; turn data files over to the Navajo Nation; and must submit all

reports and articles to the board for approval before dissemination (Wallerstein and Duran, 2006). At the same time it needs to be ensured that such processes do not themselves exclude specific vulnerable groups within indigenous communities.

There are benefits and challenges to adhering to these principles and codes. Khanlou and Peter (2005: *Part five paper 20*) discuss some of these ethical issues and their application in work on mental health promotion research with youth in Canada.

While community members may wish to move quickly into action, there may be resource constraints. In settings with few opportunities for access to information and resources, wider facilitation, resources and skills may be needed to take action or to support reflection on issues. In those contexts, training in specific areas may be a part of the empowering, co-learning process. This allows social groups to fully engage in the research process and, further upstream, to evaluate potential risks and give informed consent (Puffer et al., 2013).

Finally, research ethics boards will themselves need to include members with knowledge of these different approaches to research and their ethical requirements to be able to effectively review participatory action research proposals.

## 3.2 Bias, classification and comparability

Who participates in the research and why do some participate and others do not? This is one of the major concerns about the validity of research, whether participatory or not. This section addresses methods issues related to including people in the research.

Fair subject selection requires that the goals of the research, not the vulnerability or privilege of individuals, are the primary basis for determining which individuals and groups are involved. As much as possible, those who bear the risk and the burdens of the research should be able to benefit from the research, a matter that also relates to the prior discussion on ethics and power. A protocol using a participatory action research framework, therefore, should clearly state how participants have been included and involved and how they will benefit from participating, given the articulated purposes of participatory action research (Khanlou and Peter, 2005: *Part five paper 20*).

This starts with defining a study population – a precise description before the study starts of who will be studied during a certain time period and whether all will be involved or whether a subgroup or sample is taken to represent this study population. An example of this defining groups process is the participatory assessment by 33 households in Budh Mandir described in *Box 13*. In positivist paradigms ‘blind’ data collection is implemented by external data collectors. Participatory action research approaches, as discussed in *section 2.2*, purposively include ‘homogenous’ groups, whether of workers in a workplace, people living in a residential area or members of a community with specific health or social features. This is the group that implements the research and takes action. In contrast to positivist paradigms, it assumes that the group involved and those who initiated the research, if different, have views and values related to the issues under research. Their involvement is not by random selection and the completeness of the included group is important. It is thus crucial for researchers to declare their interests, as discussed in *section 3.1*, to know exactly which persons belong to the chosen group and to avoid errors of exclusion.

In some settings not everyone can participate directly. The inclusion criteria thus need to be explicitly stated and measures to create a dialogue with the

wider members of that group built into the process. In any research the question arises of whether non-participants – those that refuse to participate, cannot be reached, are ill or fall out for other reasons – differ in relevant aspects from those that do participate. In participatory action research, these questions about including and excluding participants also have an organizational impact, as they can affect both the knowledge produced and the ability to act on it.

If a substantial number from the social group covered do not participate, it needs to be established whether they have different opinions or experiences from those participating. Those who participate may be the most aggressive, the most ill, the most exposed or people with more income and more time for participation (Loewenson, Laurell and Hogstedt, 1994). For example, male dominance and didactic community leadership and management styles have been found to undermine real opportunities for broad-based community empowerment, particularly of women, young people and marginalized men (Baatiema et al., 2013). As noted earlier, this may be a particular problem for the most disadvantaged groups, such as undocumented migrants, substance abusers, children on the street or commercial sex workers who fear exposure or may be particularly disempowered (see *Box 28*).

The methods outlined in *Part two* offer various ways of overcoming this. In some studies participation is ensured and sustained by integrating the work within pre-existing community structures and tapping into existing networks of trust (Baatiema et al. 2013). Cornish and Ghosh (2007) in their work on commercial sex workers in India described the need to engage with sex-club owners and brothel managers to gain access to red light districts. Where there are power imbalances between groups, one option is for different groups within the ‘study’ population to be involved first through separate processes before linking with wider groups. Further, as noted in *Part two*, whatever specific method is used – mapping, ranking, diagrams, and so on – the evidence is reviewed and discussed not simply to identify the average but also to identify (and respect) differences between groups and to use this as a means of understanding problems and their causes.

Excluding key groups from the research may affect the analysis and action. Biases in participation thus need to be taken into account in interpreting the findings. Further, as mentioned, when people are excluded or lost to the participatory action research,



### Box 28: Selection bias in research among female sex workers in Madras

The shared space of brothel-based women promotes solidarity but in a research project in Madras this normally positive element was reported to work against developing community support networks. Also, social conditions made it difficult to include all groups in the participatory research.

Brothels in Madras are reportedly smaller than those commonly found in Indian cities, with most housing no more than three to four women at any one time. Brothel-based commercial sex work here was characterized by high mobility and over 30% of the women employed came from the neighbouring state of Andhra Pradesh where bosses targeted pockets of rural poverty to recruit young girls. Being from another state and unable to speak or understand the locally predominant Tamil language, young Andhra commercial sex workers were often isolated from their peers and highly dependent on their brothel-keepers. Sex workers moved between different establishments which also undermined solidarity – women rarely stayed in a brothel for more than six months with most contracts lasting just one to three months.

The premises for the brothels also regularly shifted in response to police raids or complaints from neighbours. Due to the secretive, shifting nature of brothel prostitution, clients were normally procured through brokers who also played a central role in prostitution practised by 'family girls'. These are women who continue to live within regular households but sell sex, often without the knowledge of their families and neighbours. Many family girls did not consider themselves as 'prostitutes' but as decent women making some extra money for their households. They therefore distanced themselves from street workers and brothel-based women. They considered themselves superior to full-time sex workers who service larger numbers of clients and are open about their profession. Family girls and brothel-based women had limited contact with other commercial sex-workers and even informal gatherings were limited due to fear of arrest. The women in the different groups were thus reported to be isolated, scattered and highly secretive about their profession, and unconvinced about any benefit from collective organization.

While this context and the dependency on individual brokers locks these women into unequal power relations, it appeared to be a least-risk strategy in extremely precarious circumstances.

Source: Asthana, and Ostvogels (1996)

this may affect the group's capacities to take particular actions and thus learn from those actions.

The risk of systematic misclassification is increased if key groups are excluded or if the collective discussions are not systematically based on individual inputs (Loewenson, Laurell and Hogstedt, 1994). Systematically misclassifying the outcome could also happen if those facilitating the research are themselves biased. The gender of the research facilitator may, for example, hinder an exploration of sensitive issues, such as sexually transmitted diseases (Maalim, 2006). *Part two* presents methods that draw out individual input, such as through picture codes or pocket charts, and also methods that synthesise and validate evidence collectively, such as ranking and scoring. These methods may control the risk of misclassification.

Facilitating the dialogue by interviewing maps or making comparisons, such as in wealth ranking, would draw on rather than exclude outliers as input to reflection and analysis.

## 3.3 Validity of the evidence

Concepts that are common in scientific research are internal validity (whether the change or improvement is the result of reflection and action or of something else), external validity (whether the results and conclusions can be generalized or usefully transferred to another community) and construct validity (whether the method of gathering data is appropriate for the methodology or underlying paradigm of the research). This section explores these constructs in relation to participatory action research.

The nature of research is that knowledge produced should be broadly applicable. We need to know to what extent the results could be generalized. Validity requirements are as important in participatory action research as in other areas of research but may not be assessed in the same way. Action researchers have identified five types of validity in line with their assumptions and goals (Ozanne and Saatcioglu, 2008).

These five types of validity are:

- 1 *Outcome validity* or the issue of who benefits from the resolution of the problem;
- 2 *Democratic validity* or whether relevant stakeholders in the problem participate fully in the research and the extent to which their perspectives and needs inform solutions;
- 3 *Process validity* or whether the way problems are investigated allows for ongoing learning and improvements and enables people to reflect on their social reality for learning; this is affected by the quality of the relationships in the research;
- 4 *Catalytic validity* or the extent to which the research collaborators are invigorated to understand and change social reality both within and beyond the research study; and
- 5 *Dialogical validity* or the review from critical dialogue with peers about research findings and actions. Dialogic validity requires action researchers to engage in debates to challenge the research findings for alternative explanations, inconsistencies, problematic assumptions, biases, failure to include key stakeholders, and so on. (Anderson and Herr, 1999).

Reason and Bradbury (2008) note that validity in participatory action research needs to take into account an understanding of the plurality of knowing. Understanding the plurality of knowing is not unique to participatory action research. For example, social science methods use an approach termed 'crystallization' in qualitative research that explores multiple representations of or perspectives on the same phenomenon (Ellingson, 2009). Classic social science is partly measured by the extent to which 'experts' consider the design and constructs to be valid. Participatory action research stands on the epistemological grounds that people (especially those historically marginalized or silenced) carry substantial knowledge individually and collectively. In using the workers' model, Oddone et al. (1977) argued that participatory action research is the only method that enables valid knowledge about working conditions and their health effects since it is generated by systematizing workers' experience and only they can know this reality because they live it. This view is based on the phenomenological position that 'only what is lived (experienced) is real'.

The methods for validation in participatory action research are thus collective, through the intentional

and sustained deliberative processes, outlined earlier, to take up competing ideas and wrestle interpretations until well-developed analyses emerge that the group validates (Cammarota and Fine, 2006). Given this, the validity of knowledge in participatory action research is affected by:

- how relevant the community involved perceives the issues to be;
- how far the process and methods engage experiential knowledge without losing information;
- whether the research takes into account the cultural context of the community; and
- whether the collective process of analysis is well-facilitated and rigorous.

In contrast, with questionnaire surveys, this validity depends on how far crosschecking and correction takes place within the dialogue and collective validation, with self-critical scepticism and awareness applied throughout. Pretty (1995) proposes further complementary processes to support validation in participatory action research, such as parallel observation of the process by a second facilitator or observer, triangulation of different sources of community evidence, negative case analysis and other participants of the social group checking findings. Of these, checking and correcting by a larger local group from the same community is suggested to be a strong test (Chambers, 1994).

### 3.4 Reproducing and generalizing results

Public health interventions face mounting pressure to demonstrate that programmes are effective in decreasing morbidity and mortality rates and reducing health disparities. This section explores how generalizable the results from participatory action research are and how this issue is addressed.

As noted in *section 1.3*, knowledge based on positivist approaches has established scientific standards for assessing the quality of research evidence. Randomized controlled trials are viewed as a gold standard for testing causality or the strength of an association between an intervention and outcome of interest. However, communities and complex systems involved in various forms of health policy and systems research, including participatory action research, are open and dynamic systems, with a virtually unlimited number of factors influencing

health behaviours and outcomes. To produce an effect at the community level, public health interventions thus often require tests of the cumulative impact of multiple interventions simultaneously, to achieve a critical mass with detectable effects.

Judgements of reliability, rigour and validity need to take into account the essential features of participatory action research, in both shifting power and building knowledge from action and transformation. Traditional criteria used in positivist research methods are thus not simply applicable to participatory action research.

Gilson (2012) in *Health policy and systems research: a methodology reader* notes that the criteria used to make judgments of research quality and rigour differ between paradigms of knowledge. Positivist research emphasizes validity and reliability – ensured through careful study design, tool development, data collection and appropriate statistical analysis. Research based on paradigms, such as critical theory and constructivism, considers the trustworthiness of the analysis – whether it is widely recognized to have value beyond the particular examples considered. She summarizes the different criteria and questions used in assessing the quality of research based on fixed (positivist) and flexible (reflexive) designs in Table 7 below and we make further comment on how this would apply in participatory action research.

She also notes the need for: an active process of questioning and checking during the inquiry; a constant process of conceptualizing and reconceptualizing throughout the research process;

crafted, interpretative judgements and review of initial interpretations by respondents (member checking); and explicit statements of assumptions used that may influence interpretation. This raises the question of exploring how and under what conditions a participatory action research process has produced change, rather than simply a summative judgment about whether it worked. The evidence alone cannot inform judgement on this. It depends also on: good documentation of processes, procedures and effects; assessment of significance by community members and others from outside the community; and the capacities of community members to engage in and review the process (Boothroyd et al., 2004).

A further concern is how far the knowledge gained can be more widely generalized – external validity. The purposive nature of the sampling strategy and the inclusion of a homogenous group with common social features limits generalization to other settings. Participatory action research generates new knowledge concerning particular situations or the functioning of particular systems and institutions. As the method does not separate theory and practice it is possible to aggregate knowledge from particular studies but not to generalize it. The same critique of local specificity could be said to apply to operations and ethnographic research. As shown in Table 7, the question in participatory action research is thus whether the findings generate insights, concepts, theories, learning or motivations for action that are transferable to other settings, even if the specific findings are not.

**Table 7: Criteria and questions for assessing research quality**

Fixed designs	Flexible designs	Participatory action research
<b>Reliability:</b> Is your variable measure reliable?	<b>Confirmability:</b> Do the data confirm the general findings and lead to their implications?	Was the process through which the community interrogated and validated the evidence well described? Were the findings reviewed after actions?
<b>Construct validity:</b> Are you measuring what you think you are measuring?	<b>Dependability:</b> Was the research process logical and well documented?	Was the research process participatory for all key members of the homogenous group, was it logical and well documented?
<b>Internal validity:</b> Does the study plausibly demonstrate a causal relationship?	<b>Credibility:</b> Is there a match between participants' views and the researcher's reconstruction of them?	Was the process for validating and analysing findings participatory for all key members of the homogenous group, and did it adequately review outliers and differences?
<b>External validity:</b> Are the findings statistically generalizable?	<b>Transferability:</b> Do the findings generate insights that are transferable to other settings?	Do the findings generate insights or motivations for action or reflection that are transferable to other settings?

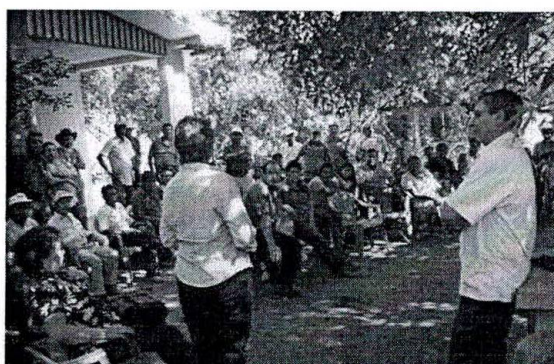
Source: Gilson (2012) with author input

There are options for addressing these issues in participatory action research. The process should include an assessment of context and provide evidence of collective validation, peer review and supporting evidence on issues such as practicality, feasibility and adaptability. This can provide information to support conclusions about what works and the conditions under which it works. Various papers reproduced in this reader provide such information, such as Falabella (2002: *Part five paper 3*) and Garwick and Auger (2003: *Part five paper 8*).

Another approach to generalization is to use the methods for meta-analysis of qualitative data, as discussed in *section 2.6*. Other forms of generalizability have been raised in ethnographic research and may apply in participatory action research. Theoretical generalizability is used which is the extent to which theoretical notions move from one context to another, for example by drawing shared lessons from case studies. Provocative generalizability measures the extent to which a piece of research provokes readers or audiences across contexts to rethink current arrangements and whether it motivates people to act (Cammarota and Fine, 2006).

A further way to address the generalizability of knowledge is through multi-country research that identifies common knowledge across different sites of participatory action research. It is also possible to triangulate with other techniques to obtain complementary data. Hence, participatory action research has been complemented by other forms of community-based research, such as questionnaires or clinical examination using probability sampling (Laurell et al., 1992). In this case questionnaires, measuring techniques and processing are carefully simplified and standardized to make interpretations accessible to community members so they can implement them themselves.

Villagers discussing participation in a research programme, El Salvador



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### 3.5 Logistic aspects

This section discusses the logistic issues that need to be considered when implementing participatory action research.

While locating research capacities and processes within communities and local health systems may overcome logistic challenges in accessing skills and resources, implementing participatory action research also raises logistic issues. The work may follow unpredictable and sometimes long timeframes. For communities this can draw on limited resources and demand creative thinking to sustain active participation, particularly when conflict arises or resources are limited. Participatory action research reports often capture the logistic challenges researchers face (*Box 29*).

Similar challenges are found in other programmes involving social participation and broader learning from this work can inform those managing logistic challenges in participatory action research. Nathan et al. (2013) studied the impact of engaging 'community participation coordinators' in a district in Australia. They found that coordinators are more able to support and facilitate community actions in health service policy and practice when they:

- build skills and confidence;
- engage communities in agendas for action;
- help community members navigate and understand the health system; and
- support advocacy with health authorities and personnel.

Those involved need to invest time and pay attention to building relationships of trust. As in other areas of research, working with vulnerable or disadvantaged groups can increase demands on those involved, as Maalim (2006: *Part five paper 10*: 187) found in work with Somali nomads:

*Similarly, the long distance between villages was quite exhausting for both the researcher and his assistants. This was further aggravated by lack of both public and private transport due to impassable roads in most of the research sites. The researcher was also forced to use armed security guards while travelling long distances between the research sites. This was very common in the northern division of Mbalambala because of bandits from the neighbouring countries, which are quite common in the district.*



### Box 29: Exploring the challenges of implementing participatory action research in the context of HIV and poverty

This study explores the challenges involved in implementing participatory action research in the context of HIV/AIDS and poverty in South Africa. The author describes a project with a group of people living with HIV/AIDS in Masiphumelele, Cape Town that took place in 2003/ 2004.

The study intended to create an opportunity for participants to engage in a participatory process aimed at self-awareness and empowerment, and to build learning in the process. Challenges were encountered from the point of view of both the researcher, who had to 'let go of control', and the participants who had to take on control. Participants struggled with issues of low self-efficacy and learned helplessness. Fluctuations in health also contributed towards alternating periods of hope and despair and these problems had an impact on their motivation to participate in the study.

Of note was that those most in need were found to be least likely to participate.

*Source: Rosenthal (2010)*

While the work may be most needed in more disadvantaged communities whose voices may be least heard in systems, such individuals are often least likely to be in a position to donate their time and energy. Even where child care and transport is provided, there are still differential costs of participation between groups, including by gender (Minkler, 2005).

Participatory research demands incentives (time and resources) for community and researcher roles. It also requires that funding mechanisms are sensitive to the opportunities and the demands of the process, not all of which can be anticipated and timed at the onset (Viswanathan et al., 2004). Bringing in resources from outside the community can be problematic and can emphasize the power and control of those supplying funds, rather than that of the participants (Rosenthal, 2010). If facilitators from outside communities also fund community meetings or reimbursements to participants, this can affect their role and introduce other sources of power in their relationship with communities. If neither researchers nor communities hold the funds this may subject the process to external procedures and timings that impact on the research.

These logistic demands create an apparent contradiction between the needs this research process aims to respond to and how easy it is to apply. Comparing two projects in Canada in a relatively well-served community in close proximity to researchers and another in a remote and under-served community, the participatory process was easier to follow in the well-served community in

close proximity and more challenging to follow in the under-served community (Ritchie et al., 2013). While raised as a 'proximity paradox' in this study, it is more likely that marginalized and disadvantaged settings will be more difficult environments for any form of research and that this can generate a risk of inverse focus, where those with greatest need are least involved, even in participatory action research.

One way of addressing these challenges is to embed participatory action research within the work of the organizations involved. However, embedding these participatory processes within the public sector can create difficulties and impose the limits inherent in a bureaucratic process. Those most invested in the bureaucratic outcome have little incentive to cede power in decision making (Chung and Lounsbury, 2006).

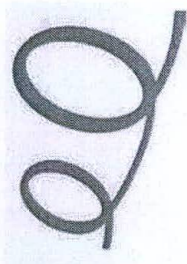
The time and resources for these issues can be built into research protocols and funding grants. There is, however, sometimes a lack of institutional support for participatory action research – for both communities and researchers – due to an inadequate appreciation of the methods. This is also a problem in formal rewards schemes. Funders hold back on funding unpredictable processes and outcomes or may set timelines and targets that are incompatible with the process (Springett and Wallerstein, 2008).

Hence, while individual studies need to plan for these challenges, such work needs longer term and more stable sources of support.

Section 4.3 explores the role of learning networks and communities of practice in providing such support.



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## **Part four**

# **Evidence & action**

*Part four cover page photo:  
Community bridge building to overcome barriers to care identified in  
participatory action research, Democratic Republic of Congo*



## Part four

# Evidence & action

This section discusses reporting, disseminating and using participatory action research. It looks at the formal peer-reviewed publications process used to disseminate much research in health systems and explores other ways in which research findings, actions taken and the institutional change produced are spread, including in the realm of policy.

Since action is embedded within participatory action research, there is an immediate local connection between knowledge and action. The wider uptake of learning from this approach and processes within it depend, however, on a more complex array of contextual, socio-political and other factors. When participatory action research processes spread horizontally from site to site, as described for example in Mbwili-Muleya et al. (2008: *Part five paper 6*) the spread may first be slow and become more rapid as the number of individuals adopting the innovation increases. Rogers proposes the diffusion of innovation theory, where five characteristics are argued to influence the pace with which an innovation is adopted:

- relative advantage (seen to be better than the idea or practice preceding it);
- compatibility (consistent with existing needs and values);
- complexity (how complex it is to apply);
- trialability (whether it can be piloted);
- observability (its visibility to others) (Rogers, 1995; Tandon et al., 2007).

On the other hand, a significant change in socio-political conditions can lead to a more rapid spread of participatory action research processes and the knowledge from them, as described at various times in history and in various regions in *section 1.2*. This section explores some of the ways participatory action research has been reported and used, and

the conditions that have enabled and blocked it. As a starting point it explores how the knowledge and learning from participatory action research is and can be reported and shared beyond the immediate community involved.

### 4.1 Reporting

Participatory research makes an effort to genuinely involve communities in the reporting and publication of the work and for participants to have an authentic role in this. This section explores the options for and issues in reporting this research.

As noted in *section 3.1*, reporting is one of the ethical questions in participatory action research and needs to be discussed and planned for at the inception. As Smith, Rosenzweig and Schmidt (2010: *Part five paper 21*) point out, participatory action research is a fluid, multifaceted, co-created, idiosyncratic process that does not necessarily correspond to established report-writing conventions. Some authors suggest that the linear, technical process in formal publication oversimplifies community realities and excludes them from the process (Young and Wharf Higgins, 2010). Added to this is the political dimension of communicating participatory action research. As noted earlier, the power shifts in this research and its role in challenging systems of thought, power and legitimation can make publication in more formal and academic media a challenge.

#### SEE PART 5: PAPER 21

Smith, Rosenzweig and Schmidt (2010) discuss ways of strengthening the reporting of participatory action research, presenting best-practice suggestions based on an analysis of participatory action research articles published between 2000 and 2008 (see also *Box 30*).

Participatory action research and other forms of participatory research are published in peer-reviewed literature, as exemplified by the papers in this reader. Many are not, however, despite their importance for the development of the field. Participatory research often concerns very applied questions whose importance is underestimated in scientific journals, particularly when the research paradigm is poorly understood. As noted in *section 2.3*, the studies using the workers' model in Italy were at the time published in a special journal, *Medicina dei Lavoratori (Workers' Medicine)*, that had the format of a conventional scientific journal and was started by the unions' Centre for Research and Documentation on Working Risks and Health Damage in 1974.

Much participatory action research is done in iterative cycles of theory or analysis and action, and many of the processes are directed at institutional and system changes, particularly in initial stages, rather than at quantitative outcomes. Given this, much work is published in grey literature as 'work-in-progress' or reported in journals not yet indexed in bibliographic databases. This means that cited evidence is weighted towards the more accessible body of publication from middle and high income countries, although systematic reviews try to find and include these unpublished studies.

Published information on low and middle income countries may not always reflect how the history, culture, economic development and institutional structures of these countries have affected their responses to policy and programme initiatives (Loewenson, 2010). For academic researchers involved in participatory action research, publication in scientific journals is a necessity for knowledge dissemination, funding and career paths. For the community directly involved, such publication is seen as less important than the publication needed for ongoing engagement or for widening alliances around the work and its implementation.

Nevertheless some form of publication is essential so that new researchers can learn and develop professionally from the pioneering paths of their predecessors, and for peer review of the work. It is thus necessary for both those involved in participatory action research processes and the publishers of journals to identify a format and style, form, language and content that are relevant and accessible to both academics and communities.

In doing this it needs to be recognized that participatory action research does not necessarily conform to established report-writing conventions; it may not use the traditional format in peer-reviewed publications of background, methods, findings, data analysis and discussion. New online journals, however, provide more scope for including appendices for more detailed narratives and visual evidence and are open access, widening opportunities for publishing and reading work from this research.

So participatory action research authors are left largely up to their own devices with regard to guiding readers through the processes described in *section 2.1*. Including direct quotes or materials from the process, such as maps and charts, provides further ways of representing community voice and more direct portrayal of the process and evidence, particularly where the methods use visual tools. This was done for example in Young and Barrett (2001: *Part five paper 14*), Maalim (2006: *Part five paper 10*) and Terry and Khatri (2009: *Part five paper 11*).

Smith, Rosenzweig and Schmidt (2010: *Part five paper 21*) noted wide variation in reporting participatory action research projects, with some articles conveying the process, outcomes and voices more effectively than others, some reflecting the creativity and passion of the authors and some having a rich narrative quality, including community voice. In a review of participatory action research papers published between 2000 and 2008, they found greater clarity when papers included discussion of seven parameters:

- 1 how the work was initiated;
- 2 the timeframe of the work;
- 3 who the participants were;
- 4 the extent of their participation;
- 5 the method or process that occurred within the work;
- 6 outcomes and/or emergent actions; and
- 7 potential future directions (if it was ongoing).

Explaining the roles of participant researchers to clarify who did what and when is helpful and important, especially since roles may shift over time. Authors need to identify and explain what their team considered to be its outcomes and actions thus far, including changes in consciousness and power (Smith, Rosenzweig and Schmidt, 2010).



### Box 30: Guidelines for best practices in reporting

- 1 Plan ahead for organizational structure – possible options:
  - Adapt conventional organizational headings.
  - Consider deriving organizational structure from project design elements or emergent themes.
  - Consider a chronological or narrative framework.
- 2 Convey the key elements of the project:
  - How was the project initiated?
  - What was the project's timeframe?
  - Who were the participants and/or co-researchers?
  - What was the extent of their participation and the nature of their roles?
  - What was the process within and/or the methodology of the project?
  - What were the project outcomes and/or emergent actions?
  - What comes next (if the project is ongoing)?
  - Consider charts, timelines, tables or other graphics to convey part or all of the project design.
- 3 Convey the experiences of co-researchers:
  - Pay attention to who is writing the article and how their voices and experiences are represented.
  - Pay attention to who is not writing the article and how their voices and experiences are represented.
  - What were the personal outcomes of the project?
- 4 Address the challenges, pitfalls and limitations of the project:
  - What were they?
  - How were they managed?
  - What can we learn?

Source: Smith, Rosenzweig and Schmidt (2010: Part five paper 21)

They suggested best practices for writing about participatory action research, shown in Box 30.

Beyond the structure, form and content of such publication, the process of producing a publication can itself shift the balance of power away from communities, particularly when they are less literate and less familiar with published work or when publication is in a language other than their own. The process of publication thus needs to balance the interests of journals and communities, and may demand time and processes to ensure that it meets the expectations of both. Chung and Lounsbury (2006: 2136) describe a situation where the process of editing a participatory rural appraisal project report to make it less threatening to its audience, led to information the community felt to be key being omitted. One participant said:

*What we were able to describe in the [document] was that there were problems with the system. We ran right into the realization that the system was the problem. And this was threatening. It is disrespectful.....You know, we're just going to completely 'dis' what you said. That's worse than patronizing.*

The community in this study was determined to regain power in the process and returned to the negotiated rules of empowering co-investigation. Two versions of the report were then produced, an 'official' edited version and a second unedited version that was the 'source document'. This latter document included richer information and was the deliverable the community wanted. When the two documents were finally put up for vote by the community council governing the work, a unanimous approval of the second was followed by a standing ovation (Chung and Lounsbury, 2006).

There may be scope for increasing publication of participatory action research, given the growth in information and media for communication. Also people's understanding of health policy and systems research has shifted to include broader concepts of social, cultural and economic context and a wider range of methods (Joint HSR Project, 1996), focusing on lived experience and the macro level distributions of power, income and other resources (WHO, 2008).

## 4.2 Using the research in health systems and policy

Participatory action research has played a direct role in health systems, as outlined in *section 2.7* and examples are cited throughout this reader. This section makes the case that health systems would benefit from participatory action research driven empirical work being communicated to policy-makers.

Participatory action research generates unique knowledge based on a wealth of information from those directly involved. It acknowledges complex causality and builds knowledge from action. We contend that this makes it invaluable to real-world policy-making (Loewenson et al., 1994; Loewenson et al., 2010).

This section gives examples of how participatory action research has contributed to policy or institutional changes in health systems. It discusses the strategies for how this was achieved and explores the challenges in using this research in health systems policy.

Participatory action research's critique of how knowledge is produced and framed, the epistemological alternative and subject-object transformation it entails leads to the generation of new questions, fresh perspectives and ultimately new knowledge (Loewenson, Laurell and Hogstedt, 1994).

The centrality of community involvement at every stage of the research process in this approach makes research a less elitist enterprise and yields a wealth of insider information and insights that an outsider's framing of the issue may miss (Loewenson et al., 2010; Minkler et al., 2012).

This is illustrated by Aryeetey et al. (2013: *Part five paper 18*) in their study using participatory wealth ranking techniques in Ghana. They demonstrate

a multidimensional community conceptualization of poverty that takes diverse factors into account, including physical appearance and social marginalization. They also highlight how poverty is conceptualized differently across different communities, even within the same region of Ghana. A frame of reference that views poverty in strictly monetary terms fails to identify those perceived to be in most need at the community level (Aryeetey et al., 2013).

Other research using participatory action research processes from east and southern Africa have demonstrated that communities raise more structural determinants of health and disease than health workers, and identify social, cultural and familial factors in health that may require insider knowledge that other methods simply cannot yield (Loewenson et al., 2010).

The emphasis on lived experience and primacy given to context leads participatory action research to reject single factor causal models and instead look to more holistic models that acknowledge the role of multiple factors and causes in explaining reality (Loewenson et al., 1994). This kind of research thus looks at the effects of and interactions between social, political, economic and environmental factors in producing health outcomes (Minkler et al., 2012). Recognizing that no single method can capture this complexity, this research increasingly embraces mixed methods to achieve its goals. By leveraging partnerships, it brings local knowledge and perceptions together with quantitative research to make meaningful policy change, as highlighted in the examples from California discussed later (Minkler et al., 2012).

As noted earlier, models that aim to neatly determine cause and effect arguably provide a more partial view of the world. By embracing complexity, participatory action research can be useful to policy-makers who need answers to solve real-world problems, as opposed to estimations of the impact of particular interventions, devoid of context considerations and other influences.

This advantage is reinforced by participatory action research emphasizing knowledge as a basis for action, as opposed to as an end in itself which greatly enhances its relevance to policy. As discussed in *section 1.3*, the research focuses on questions that have a direct bearing on social need and real-world problems, and aims to achieve what

Minkler et al. term 'a balance between knowledge generation and intervention' to benefit both the scientific community and the community involved in the participatory action research process itself (Minkler et al., 2012:12).

Further, participatory action research processes build capacity, so communities can identify problems and develop 'down to earth' solutions to 'inspire policy change', providing potential learning for policy-makers (Loewenson et al., 2010:15). This reader and the empirical papers provide numerous examples of this. The work reported gives voice to those at the ground level who are often in the best position to gauge their needs and the information based on these research processes allows policy-makers to align their policy agendas and decisions to these locally-perceived needs and demands, sometimes saving resources (Loewenson et al., 2010).

While a definitive causal relation between 'voice' and policy change is difficult to establish, reviews of evidence in low and middle income countries suggest that involving community members and local personnel in setting priorities and carrying out research improves the performance of health systems and population health outcomes, especially

in relation to health promotion and public health activities (Loewenson, 2010).

At the same time, participatory action research and participatory processes more generally have been charged with neglecting issues such as elite capture or 'civil society failure' (Mansuri and Rao, 2013). Participatory action research recognizes the potential for elite capture at the local level and acknowledges the role of social conflict in knowledge, accepting that communities are not homogenous, as discussed in *section 1.5*. The research specifically addresses issues of class and race and the power dimensions in knowledge and systems. It brings to the fore the perspectives of groups that would often not be heard or would be drowned out when other research methods are used, an essential insight if policies are to effectively address their concerns (Loewenson et al., 2010).

Participatory action research thus has much potential to be useful to policy-makers. However, to achieve this potential, policy-makers need to be sensitized to an alternative conceptualization of communities, viewing them as storehouses of knowledge based on lived experience as opposed to primarily sources of 'problems and challenges' that need to be addressed (Minkler et al., 2012:12).



*Summarizing the findings of focus group discussions, Philippines*

**Table 8: Policy issues addressed in published papers included in part five of this reader**

Authors and year	Policy issues addressed	Study setting	Policy or managerial changes resultant
Wang et al. (1996)	Female empowerment using photo-novellas	China	Local provision of day care, midwife services, scholarships for girls
Minkler (2000)	Community action to build healthy communities	USA	Improved sanitation infrastructure, changes in environmental regulation rules
Garwick and Auger (2003)	Health needs of American-Indian children with chronic conditions	Minneapolis, USA	Development and dissemination of culturally-sensitive material on asthma management
Kawakami et al. (2006)	Raising awareness on occupational safety for informal workers	Cambodia, Mongolia, Thailand, Laos and Vietnam	Changes in occupational safety programmes and development of company safety and health policies
Rasmussen et al. (2006)	Occupational health at turbine factories	Denmark	Managerial changes to make safety a collective responsibility as both intervention and outcome
Mbwili-Muleya et al. (2008)	Community dialogue on planning and budgeting at the primary care level	Zambia	Managerial changes incorporating community input, use of participatory action research (PAR) tools to address issues
Terry and Khatri (2009)	Village level management of pig waste	Fiji	Installation of new pig management system
Estacio et al. (2010)	Generating community knowledge to stimulate social action to improve health	Ayta community, Philippines	Local government included recommendations into local planning, literacy centre built
Inmuong et al. (2011)	Developing regulations to control public health hazards	Thailand	Development of regulations to control health hazards
Borgia et al. (2012)	Prioritizing health services in rural areas	Uruguay	A pilot using PAR developed a model for participatory health services in 12 regions
Minkler et al. (2012)	Community initiative to prevent obesity	California, USA	Infrastructural improvements including better lighting, safe walking paths and phone systems to report hazards detected
Othieno et al. (2009)	Creating mental health awareness	Kenya	Hospital psychiatrists and community health nurses increased provision of information to community meetings and groups. An occupational therapist started working with children with intellectual disabilities in one of the community organizations
Aryeetey et al. (2013)	Community conceptualization of poverty and premium exemptions to the national health insurance scheme	Ghana	None
Laurell et al. (1992)	Occupational health at a steel factory	Mexico	Redefined collective bargaining rules

In addition to the discussion on the use of participatory action research in health systems in *section 2.7*, Table 8 gives examples from different countries in all regions.

These examples demonstrate the use of these approaches in bringing about policy or managerial change in health systems, based on the content of the published papers. One limitation faced by participatory action research reports is that they may not include details of the changes brought about as these may have taken place subsequent to the production of the paper, as part of a longer term process. The table thus includes only papers where policy or management changes were reported or evident and does not make assumptions for papers where they are not, except to note that this important information is not included in the published paper.

These papers suggest that participatory action research is more likely to be used in health policies that include community participation as a major component, as was the case with the strategy for 'Healthy Communities or Cities' adopted as a health promotion policy in the Americas (Minkler, 2000; Pan American Health Organization, undated). The more successful experiences of collaboration between local authorities and organized local populations seem to be those based on a common agenda founded on the right to social participation.

An example of this is given in the case of Bogotá described in this section (Grupo G. Fergusson and Secretaría Distrital de Salud, 2007). Some papers indicate the intention to influence policy although they do not always report on the outcome. Liu et al. (2006: *Box 24*) used participatory research processes in China to establish a democratic dialogue between a group of elderly citizens, government officials and village leaders, and a local government action plan for health promotion to meet the health needs of elderly people. Byrne and Sahay (2007: *Box 26*) proposed a model for involving users of an information system and those affected by it in its design.

Minkler et al. (2012) highlight some important practices in facilitating the incorporation of participatory action research into policy. First and foremost, they cite the need to build and maintain effective partnerships that include a range of relevant stakeholders. In addition to researchers and communities, they suggest an effective strategy to ensure the desired outcome is to involve local

leaders with a shared vision (Minkler et al., 2012). They demonstrate this with an example of a community in California that successfully engaged with city officials to develop walking spaces to address obesity in the community (Minkler et al., 2012). Other examples that highlight the centrality of this factor include Minkler's paper on building healthy communities in the USA (2000), as well as the work of Inmuong et al. (2011: *Part five paper 9*) on developing regulations to control public health hazards in Thailand.

In line with their conceptualization of communities as storehouses of knowledge and wisdom, they emphasize that communities should be encouraged to both identify problems and come up with solutions to these problems (Minkler et al., 2012). In addition to the California example, mentioned earlier, this approach has been successfully applied in other instances in the USA (Minkler, 2000). Other examples include those from rural China, where disadvantaged elders successfully used participatory action research to influence policy on issues directly affecting them (Liu et al., 2006), as well as from Fiji, where Terry and Khatri (2009) report on the use of these processes in resolving the problem of pig-waste at the village level.

Another important practice, keeping cultural sensitivities in mind, is capturing community perspectives and ensuring the long term sustainability of the partnership. This implies harmonizing the research approach and process with community culture, even if this entails slowing down the project. This is particularly important in tribal communities, where approaching tribe elders and explaining the research and desire for collaboration are key to success (Minkler et al., 2012). Successful participatory action research projects have followed this approach, for example in the project examined by Garwick and Augur (2003: *Part five paper 8*) on developing culturally appropriate interventions to address asthma among American-Indian children.

In common with other authors (Loewenson et al., 2010) Minkler et al. (2012) advocate the use of multiple methods to facilitate policy action, including hard numbers, personal experiences and simple yet eye-catching presentation such as graphs and charts. The importance of multiple methods is widely recognized and this is a feature of most of the empirical literature that has had policy impact (Minkler, 2000; Rasmussen et al., 2006; Inmuong et al., 2011).



## Box 31: Summary of enabling factors and blocks to using participatory action research in health systems policy

### Advantages

Drawing on the text in the reader, policy makers can benefit by using the knowledge from participatory action research because it:

- Provides a wealth of information and perspectives from those directly involved in health systems that may otherwise be lost to policy-makers;
- Acknowledges the role of multiple factors and causes in explaining reality. It is thus useful for policy-makers who need answers to solve real-world problems in systems, taking contexts into account, rather than specific interventions that control for the role of context;
- Involves and draws knowledge from action and so addresses questions of implementing policy;
- Gives visibility to experience, knowledge and perspectives of diverse groups, including those whose voice would otherwise not be heard, which is essential for policies to effectively address the concerns of these groups; and
- Enables policy-makers to align their decisions with locally-perceived needs, demands and capacities.

Some socio-political contexts or areas are particularly favourable for participatory action research and its impact on policy and health systems as illustrated in this reader. Democratic institutional environments generally tend to promote social participation in decision making, particularly when it is part of the legal framework, as in Brazil. Similarly, participatory action research turns into a powerful tool for strong civil society organizations and trade unions that embrace the values of social justice and the right to health, popular participation and participatory democracy. As demonstrated in the examples in this reader, participatory action research (and community-based participatory research) have played a role in policies relating to rights, autonomy, discrimination or identity and to social determinants of health that demand common understanding and coordinated action across communities, scientists, experts, policy-makers and services in different sectors.

### Strategies

Various strategies facilitate the use of evidence from participatory action research in policy, including:

- Organized and engaged communities that effectively use the political, institutional and social space to influence policy;
- Effective, culturally appropriate partnerships between communities, local leaders and researchers;
- Measures that demystify, explain and make policy-making processes clearer and more accessible to communities;
- Use of multiple sources and forms of evidence in policy development, including numbers, visual information and experiences.

### Challenges

At the same time, various barriers have been identified in the reader, including:

- Some technical and policy actors are reluctant to accept different forms of knowledge or are uncomfortable with the idea and do not consider framing problems and generating knowledge as outcomes of social and power relations;
- Poor understanding and reporting of methods used by participatory action research;
- Logistic challenges, including long and unpredictable time-frames;
- The context specificity of knowledge generated.

The role that visual media plays in enabling policy impact is backed by empirical evidence from a number of studies (Minkler et al., 2012). These include a project in China that used photo-novellas to bring about policy change that empowered women (Wang et al., 1996: *Part five paper 13*), and work by Kawakami et al. (2006: *Part five paper 12*) on using visual media, among other processes, to bring about workplace improvements in the informal sector across five Asian countries.

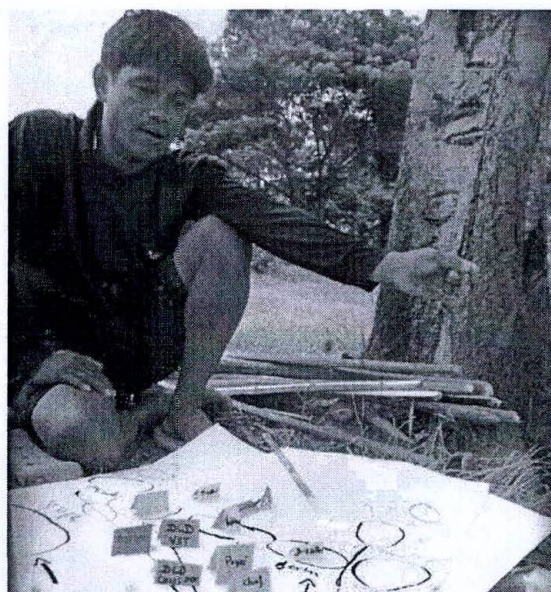
Minkler et al. (2012) advocate that researchers work within communities to ‘demystify’ and explain the policy-making process. Communities can then identify opportunities where their inputs may make a difference as well as understand the constraints in incorporating their feedback (Minkler et al., 2012). Such an approach is well illustrated by work in the USA (Minkler, 2000; Minkler et al., 2012) as well as by the work of Mbwili-Muleya et al. (2008: *Part five paper 6*) in Zambia. The latter is a good example of the potential role of this ‘demystification’ process in organizing meaningful community involvement in planning and budgeting processes for primary care level facilities.

While the factors summarized in *Box 31* make it possible to incorporate specific participatory action research processes into policy, there are other wider enablers. The presence, strength and democratic functioning of community organizations and workers’ unions and associations can facilitate change, particularly if they are embedded within a favourable socio-political or legal context. Two examples of this are described in the workers’ model in *section 1.2* and the Integrated Social Management Scheme in Bogota, Colombia, described in *Box 33*.

While those applying participatory action research must take the lead in explaining the methods and the basis for the knowledge generated, agencies funding research and academic institutions also play a role. These institutions can enable participatory action research by how they prioritize different types of research for funding. Increased funding for emerging fields such as participatory action research may contribute to a wider range of research approaches being used in health policy and systems research. This would address the limitations inherent in existing hierarchies where evidence from randomized controlled trials and quasi-experimental studies is privileged over that generated in post-positivist approaches, including participatory action research.

The factors highlighted increase the likelihood that the participatory action research will be translated into policy. It is however vital to strike a note of caution about attributing specific socio-political or policy changes to participatory action research. Policy change is complex, dependent as it is on a host of factors coming together at a particular opportune time (Kingdon, 1995). In such a situation, causal attribution to a single factor or process is virtually impossible, irrespective of the methods used or analytical frameworks adopted. In participatory action research however, there is an added layer of complexity, since the success of the research is as much about changes to institutional and policy processes as it is about changes in outcomes. The need to simultaneously identify and tease out its role in both policy and process change makes attribution all the more challenging.

The literature featured in this reader used participatory action research to effect policy change largely at the local level, rather than national or provincial levels. With the major focus of this research on strengthening social power and control over knowledge and on taking action and learning from direct transformations of institutions and processes, its locus at the community level is not surprising. The examples of government uptake of the work are more common therefore at local government level, as in the example of health services in Lusaka (Mbwili-Muleya et al., 2008: *Part five paper 6*) or in the use of participatory health impact assessment in Thailand (Inmuong et al., 2011: *Part five paper 9*), where communities have greater possibility of being more directly involved in the change.



Mapping information flows across actors, Thailand

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### Box 32: Community research at a pivotal moment: supporting primary health care in Zimbabwe

In 2008, in the midst of economic decline and a cholera epidemic, comprehensive primary health care appeared to be particularly suited to addressing the challenges and health needs in Zimbabwe at that time. Yet it was not certain that primary health care would be central to the national health strategy. Powerful medical lobbies and middle-income urban populations were also keen for resources to be used to restore the central hospitals which had also declined over the five years prior to this.

To support the voice of communities in the national policy debates on health taking place with the formation of the government of national unity, the Training and Research Support Centre (TARSC) working with the Community Working Group on Health (CWGH) carried out a participatory situation assessment of primary health care in 20 districts in Zimbabwe in March 2009. The assessment provided evidence on the conditions of community health at the primary level of the health system and exposed the views and aspirations of communities and frontline health workers. It supplied the grounds for and the inspiration to rebuild Zimbabwe's health system from the bottom up. Issues and options from the local level were available for wider discussion and input into the national primary health care strategy. Most importantly the research itself was implemented by teams from communities and frontline health workers at community and local level in the districts who, in the process, raised the profile of their views in the national health strategy dialogue.

At a one-day stakeholder review meeting, the findings of the assessment were presented to policy and sector stakeholders at the national level by personnel from the 20 districts involved. The meeting proposed that primary health care be given priority as the key strategy for recovery of people's health and the recovery of the health sector overall. Specific concrete proposals were made for how to take this forward and a taskforce was set up to motivate the implementation of the proposals.

The National Health Strategy 2010-2013 made reference to this research and the Health Sector Investment Case (2010 – 2012) made it clear that the government would focus on revitalizing the primary health care approach to address the health needs of the nation. The research was cited in this document as follows:

*The same was reinforced in the Assessment of Primary Care in Zimbabwe (2009) which clearly articulated the need to put in place a national primary health care strategy, backed by clear service entitlements, with resources effectively applied to community and primary care levels of the health system as an entry point to wider primary health care oriented changes.*

A combination of timely evidence linked to community voice, the engagement of national stakeholders, and linkages between researchers, civil society and receptive personnel within the policy and senior management levels of the Ministry of Health combined to enable the research to act as a bridge between community aspirations and national policies and plans at a critical time.

Source: TARSC, CWGH (2009)

*Nursing Health workers and communities  
jointly review progress in primary health care,  
Zimbabwe*



© CWGH 2008



### Box 33: Using participatory action research in the Bogotá primary health care programme

In 2002 the Bogotá government adopted a social policy based on social, economic, cultural, civic and political rights. A continuous process over several decades by the Guillermo Fergusson Group passed through stages of doing direct community work in poor areas, establishing a school to train popular health leaders ([www.grupofergusson.org/index.php/escuela](http://www.grupofergusson.org/index.php/escuela)), involving these leaders as officials at the Health Secretariat of the Bogotá government and implementing its integrated social management (*Gestión Social Integrado*).

A participatory action research methodology was applied systematically during all these stages, with the integrated social management being based on this as government policy. A specific method was designed to draw and organize evidence on community needs. The integrated social management system was integrated into a Bogotá health programme called '*Salud en Tu Casa*' (health at your home) and conceptualized as a primary health care strategy to work directly with communities surrounding health centres, particularly in poor neighbourhoods with multiple health and social problems. To do so, community workers formed 'existential circles' of families using Freirean participatory action research approaches to identify and develop conditions for physical, mental and social well-being.

These 'existential circles' provided the homogenous action group for clusters of families to strengthen practices related to health, the environment and social welfare and to build the necessary organization to further demand their right to health and to a decent life. The scale was wide – 297 such 'existential circles' functioned during 2011, with 30,169 participants. They had support from the authorities for community initiatives and the groups identified 71 different themes, ranging from health education to gender relations.

Sources: Grupo G. Fergusson and Secretaría Distrital de Salud (2007)

Attempts to incorporate participatory action research findings into national level policy-making are hampered by questions about context-specificity, subjectivity and generalizability, as discussed in *section 3.4* or by concerns that participation is being used only to validate decisions already taken (Deng and Wu, 2010). The epistemological approach in this research is a potential barrier to its use in policy. While the emphasis on solving real-world problems and the interdisciplinary approach make this research relevant for policy-makers, it may also be a poor fit in the silo-like structures that dominate decision-making (Rifkin, 2009).

Conceptualizing knowledge as an outcome of social and power relations leads to examining purportedly value-neutral and technical questions surrounding health systems through the lens of class, race and ethnicity – something that technocrats might not always be comfortable with or may associate with activist rather than scientific interest (Loewenson et al., 2010). Debates on the methods used and the different criteria for judging validity and reliability as well as poor understanding and reporting of these issues compound this reticence, as discussed in *section 3.3*. The dominance of disciplines such as

epidemiology and economics that are grounded in the positivist paradigmatic frameworks of health-systems research also work against the inclusion of this research in high-level policy-making (Rifkin, 2009; Loewenson et al., 2011: *Part five paper 1*).

The lack of understanding of alternative paradigms has led to participatory action research processes sometimes being characterized as 'interventions' that either 'succeed' or 'fail'. This ignores the direct role of knowledge generation processes in transforming institutions and the role of transformative action in generating knowledge (Morgan, 2001; Rifkin, 2009).

The limitations discussed earlier, such as the site and context specific knowledge generated, can also lead to the approach being discounted by policy-makers looking for generalizable lessons (Morgan, 2001). Participatory action research may pose logistic problems for health policy-makers, as it does for researchers, as discussed in *section 3.5*. The longer time-frames and unpredictable outcomes may not suit the rigid deadlines and processes in policy-making (Morgan, 2001; Parry and Wright, 2003; Loewenson et al., 2011).



### Box 34: Integrated health model in Guatemala: a continuously participatory scheme

The Integrated Health Model (MIS or *Modelo Integrado de Salud*) in Guatemala aimed to strengthen primary health care throughout the public health system, based on five principles: the right to health, strong public institutions, intercultural relevance, gender and environment. The model is a collaboration of a non-state institution, the Instituto de Salud Incluyente (ISI) (the institute for inclusive health) and the Ministry of Health. Health workers come from the communities where they work and are supported by local teams and a national group. The clinics in twelve regional health departments with 24 territories and 89 health clinics cover a population of about 200,000 with individual personal care and family visits. They work with community organizations on community activities such as environmental or social actions. The programme has reduced child under-nutrition and mortality and maternal deaths, and has improved the uptake of vaccination and health care.

This model has applied participatory action research in decision making with local health workers and officials, community groups and leaders, and Mayan therapists and midwives. An initial research project carried out by a group of professionals and health workers in 2000/2001 included 13 focal groups and in-depth interviews with health workers, trade unions, community groups and leaders, and Mayan therapists and midwives. This research informed the basic principles of the model, with a pilot that actively involved health workers, indigenous healers (midwives, Mayan and popular therapists), community groups and leaders, and community councils.

Participatory methods were not only used in the design and decision-making processes. A 2013 evaluation of the system also used a participatory approach and implemented a total of 13 focus groups with community-level personnel and in-depth interviews. The evaluation triangulated qualitative data, quantitative administrative data and cost calculations to validate the results and this revealed a high degree of concordance. The evaluation showed that the system has been very successful in strengthening primary health care, mainly due to the capacities and work organization of the frontline personnel and its systematic relations with the population and Mayan therapists.

Sources: INS (2002); ISI, MMN (2012); Feo and Tobar (2013)

At the same time, national level process changes have been associated with work on participatory action research as described, for example, in Box 32 on page 96. Policy changes across international borders associated with this approach have also been reported, as shown in Box 20 in section 2.5.

Participatory action research processes that start as a means of transforming the situation of a group or community around a specific problem have the potential to influence or transform processes in national institutions and health systems. This could happen when:

- their content is relevant and generalizable to a broader context;
- the work is aimed at a broader institutional transformation; and
- social participation and control are part of the institutional and legal framework.

This is more likely to happen in democratic institutional environments that generate new power

relations and set the ground for or provoke changes in institutions and policies. They can provide space for civil society associations or political organizations that embrace the values inherent in the right to health, in social justice, popular participation and in participatory democracy.

One example of this is in Bogotá, Colombia, a strong terrain of Freirean popular education and the home of Fals Borda (see Box 33). The Integrated Health Model in Guatemala cited in Box 34 provides further lessons on incorporating participatory action research into policy and institutions.

Borgia et al. (2012: *Part five paper 17*) describe a project that pursued the transformation of a segment of the health system using participatory action research. It aimed to change an unacceptable marginalization of rural health clinics in Uruguay after the National Integrated Health System was created in 2007. It also applied Freirean participatory action research approaches as a political strategy to pressurize the Ministry of Health and the government.

Evidence gathered from communities and health workers was presented and discussed in regional forums in 19 provinces. The 900 participants from 50 localities discussed and agreed on proposals for rural health that were presented to and discussed with health authorities. The participatory action research was backed by intensive advocacy on the findings and proposals. The study raised the lack of visibility of rural health and the health authorities announced their intention to launch a rural health plan as one of the priorities. This was partly due to their policy commitment to address social inequality and partly due to the findings from the research and the mobilization of communities around it (Borgia et al., 2012). Batista et al. (2010: *Part five paper 15*; *Box 35*) describe how such social participation and participatory processes are institutionalized in the health councils in Brazil. Health councils represent a massive effort in social participation but also point to the challenges in using this approach on such a scale. While they integrate some features of participatory action research, such as in their cycles of dialogue, conflict and consensus, they do not fully follow the participatory action research process (Labra and Giovanella, 2007).

These examples demonstrate in a number of different countries and contexts how participatory action research can catalyse other participatory practices in health systems. They also demonstrate that participatory processes, such as participatory action research, need to be renewed and reviewed to avoid losing their grounding in communities. As a paradigm that links knowledge to change

through actors that are more directly involved in these processes, the uptake of participatory action research in national health systems is only partially addressed through the methods used. Even in settings where there is political support and space for participatory transformation within health systems, the Brazilian experience shown in *Box 35* suggests that asymmetry in knowledge and power persists. While participatory action research has been used to contribute to innovation in health systems, it may also be needed to sustain and deepen social participation.

To address these issues successfully, participatory action research needs to seriously tackle the task of developing methodologies and techniques to move from 'local experience' to 'national health systems' and to enhance its day to day relevance to policy-makers (Loewenson et al., 2010). This may take advantage of political contexts that provide support and resources for such national application, as described in *Box 32*. It may also tap the opportunities for this from new information technologies discussed in *section 2.4* and the methods for meta-analysis outlined in *section 2.6*.

At the same time, there are ways to reduce or overcome the barriers identified and to make better use of windows of opportunity for participatory action research to generate knowledge in health policy and systems. The methods need to be more effectively communicated, more widely understood and rigorously applied. As discussed in *section 3.4*, thoroughly explaining the methods, ethics,



### **Box 35: Brazilian health councils as an institutional platform for participatory methods**

The Brazilian constitution was developed in 1988 after a highly participatory process. It recognizes the state's obligation to provide health care by means of a decentralized single public health system. The health law stipulates that there should be health councils at the municipal, state and national level with representatives from the government, health professionals, health workers and elected members of user organizations (trade unions, neighbourhoods or other social organizations and churches). These councils were to be channels for social control in planning, decision-making and activities in health services.

An evaluation of evidence from 2003/2005 on their performance found shortfalls in the participatory culture. There was less information and knowledge exchange between government and communities than between government and health service representatives. Efforts to change procedures and build more participatory processes still don't entirely escape from the unequal and asymmetric structure of society.

*Sources: Batista et al. (2010: Part five paper 15)*

data quality and validity, as well as triangulating evidence from this research with other forms of evidence, as done for the collective questionnaire work in Latin America (Laurell et al., 1992), is all the more important in a field where results cannot be verified by others using the same data sets, unlike in more positivist research (Loewenson et al., 2010).

The next section further discusses the role of learning networks and communities of practice in supporting positive practices, strengthening capacities, exchange and peer review, and developing methods in participatory action research.

### 4.3 Learning networks and communities of practice

Most participatory research takes place at the local level and the primary relationships are between communities and the organizations that provide skills, facilitation and resource support to the process. Institutionalizing the work within the local context demands careful consideration of form and process, and uses local networks to build longer-term bridges between participatory researchers and communities. These connections tend to be time bound for the duration of the work but may also become more formalized, with joint governance mechanisms and dedicated time and funding for the collaboration processes (Cheadle et al. 2002; Williams et al., 2009).

While most of this research occurs at local levels of health systems, with the evidence being used at the national level, some issues demand analysis and action at wider levels. Also, local efforts and findings may engage with struggles over or contributions to broader-level change. As noted earlier this has become more evident as:

- health determinants and influences on the design and functioning of health systems are increasingly cross border and international;
- information flows and social connections become more global in scale; and
- inequities between health needs and health sector resources and services increase and gaps between knowledge and practice widen, with marginalized social groups within countries sharing the experience of the same groups in other countries.

Taking local institutional forms to the international level introduces many complexities. However, as

participatory action research methods are more widely applied, those using them are forming learning networks to exchange experience, get advice and review, and to build forms for meta-analysis of common findings and more generalizable knowledge.

One example of this is the pra4equity learning network in the Regional Network for Equity in Health in East and Southern Africa (EQUINET; [www.equinetafrica.org](http://www.equinetafrica.org)). It was initiated in the 2000s as a network of participatory action research sites across ten countries. This aimed to build knowledge on: community and health worker interactions in local health systems; primary health care approaches to HIV and AIDS services; and other areas of health system functioning with wider relevance to health equity within the region. With studies all following a similar design, exchanges across the learning network were used to identify common findings and generalizable knowledge on health systems across the sites, and to provide mutual support and mentoring on methods, share experiences and peer review findings (Loewenson, 2010). Other such networks exist as communities of practice, e-learning networks, web-discussion fora, learning communities and thematic groups. They provide a forum for practitioners who share a common interest in developing capacities and sharing experience.

Examples include:

- Participatory Research & Action Network ([www.pran-bd.org/](http://www.pran-bd.org/))
- Participatory Research and Action Group Nepal (PRAG) ([www.healthynewbornnetwork.org/partner/participatory-research-and-action-group-nepal-prag](http://www.healthynewbornnetwork.org/partner/participatory-research-and-action-group-nepal-prag))
- *Science shop* movement in Europe
- PRIA (Society for Participatory Research In Asia), India ([www.pria.org](http://www.pria.org))
- Praxis Institute for Participatory Practices ([www.praxisindia.org](http://www.praxisindia.org))
- Networks linked to the IDS Participate, Power and Social Change team ([www.ids.ac.uk/team/participation-power-and-social-change](http://www.ids.ac.uk/team/participation-power-and-social-change)) and to the Participate Initiative IDS ([www.participatorymethods.org](http://www.participatorymethods.org))

Those involved in participatory action research have called for a widening of such networks. In the 2010 Global Symposium on Health Systems Research, researchers working with participatory action research suggested that a learning network

could facilitate the exchange of methods and work by bringing together researchers across different participatory action research sites. It could provide opportunities to share local learning and a forum to create a community of practice as an important part of building constituency, credibility and capacity for health policy and systems research globally (Loewenson et al., 2011: *Part five paper 1*). This was further reflected in the closing plenary session of the 2010 symposium in the plea from Etiayo Lambo, Nigeria's former Minister of Health. He called for any strengthening of health policy and systems research to involve policy and practice communities in the research process 'using problem-solving, action-oriented approaches like operations research and participatory action' (Lambo, 2011).

The published papers reproduced in full in *Part five* and those in the reference list on page 99 indicate

the range of work underway. They offer a glimpse of the significant body of work in participatory action research, the broad range of this work, and the learning, experiences and critical reflections in implementing or trying to implement participatory action research, particularly in health policy and systems research. The papers provide more detailed information on methods, debates, challenges and limitations, as described in various parts of this reader. They also provide a window to the people involved in the research and their role in using the transformative power of the approach – inevitably, with varying levels of success.

Without people there is no participatory action research. We thus hope that this reader does not sit on a bookshelf but is found in places where people meet, engage, debate and shape action, with covers worn and evidence of many hands having turned its pages.



EQUINET pra4equity network members, Uganda



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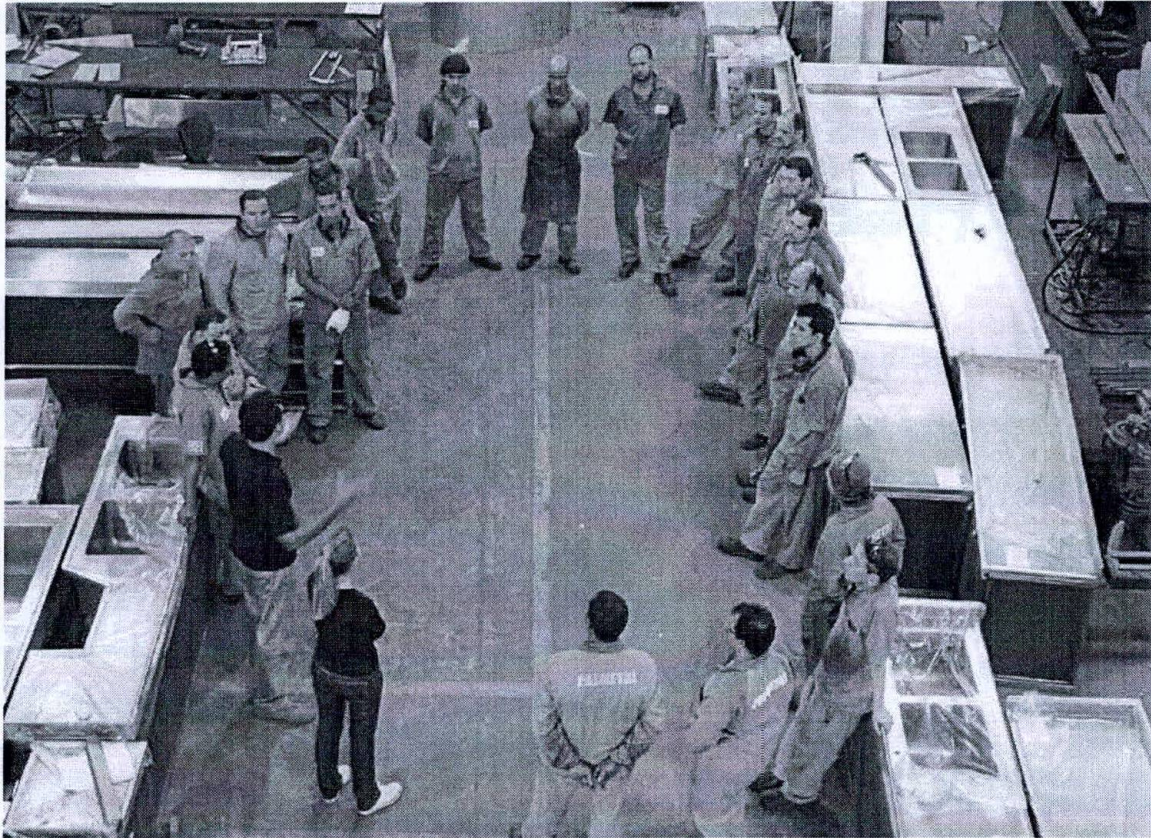
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# **Part five** **Empirical papers**

*Part five cover page photo*

*Workers meeting in a stainless steel ecodesign company, Brazil*



## Part five

# Empirical papers

This section in this web version provides links to a selection of twenty-one papers that demonstrate the concepts and methods in participatory action research and their application discussed in the reader. The table on page 114 lists the selected papers under their section headings and gives the title, author, date and region of focus. Full bibliographic and copyright details are given separately before each section's papers. To comply with journal clearances we provide the full papers only in the hardcopy version of the reader. In this electronic version of the reader we provide url links directly to the papers in the journals under each paper citation listed on page 115 onwards. Pasting the url provided in your browser will take you to the paper. Should any links not function please notify [admin@equinetafrica.org](mailto:admin@equinetafrica.org).

The selection includes peer-reviewed published reports and journal papers. These are highlighted in particular sections of the reader and are presented here accordingly although some feature in more than one section.

While the papers do not cover a specific date range, most of them were published after 2000. They are from different regions (North America, Latin America, Europe, Asia, Pacific, Africa)

and cover dimensions of health policy and health systems, including policy and action on the social determinants of health.

In each paper, we aimed to cover as many of the following elements as possible but some papers clearly represent just one or more of the key features.

- Clearly define problems relevant to health systems;
- Include the cycle of processes in participatory action research, including action and reflection;
- Provide clear information on methods;
- Report findings and actions;
- Assess and report on the impact of actions on health, health systems and social power;
- Reflect on or evaluate the work and methods or role in health policy and systems research and health systems; and/or
- Provide evidence of the institutionalization of the method.

These papers exemplify different aspects of participatory action research. There are many other papers listed in the reference list at the end of *Part four* of the reader and in the boxed examples and we encourage readers to read these papers too.

Table 9: List of empirical papers

Paper number and title	Authors in full and year	Region
<b>Papers for Part one: Concepts</b>		
1 Raising the profile of participatory action research at the 2010 Global Symposium on Health Systems Research	Loewenson R, Flores W, Shukla A, Kagis M, Baba A, Ryklief A, Mbili-Muleya C and Kakde D (2011)	Worldwide
2 The application of participatory action research in Latin America	Fals Borda O (1987)	Latin America
3 Experiencias y metodología de la investigación participativa	Falabella G (2002)	Latin America
4 Critical reflections on social injustice and participatory action research: The case of the indigenous Ayta community in the Philippines	Estacio EV and Marks DF (2010)	Southeast Asia
5 Use of participatory, action and research methods in enhancing awareness of mental disorders in Kariobangi, Kenya	Othieno C, Kitazi N, Mburu J, Obondo A, Mathai M and Loewenson R (2009)	East Africa
6 Consolidating processes for community–health centre partnership and accountability in Zambia	Mbwili-Muleya C, Lungu M, Kabuba I, Zulu Lishandu I and Loewenson R (2008)	Southern Africa
<b>Papers for Part two: Methods</b>		
7 Participatory research on workers' health	Laurell AC, Noriega M, Martinez S and Villegas J (1992)	North America
8 Participatory action research: the Indian Family Stories Project	Garwick AW and Auger S (2003)	South Asia
9 Participatory health impact assessment for the development of local government regulation on hazard control	Inmuong U, Rithmak P, Srisookwatana S, Traithin N and Maisuporn P (2011)	Southeast Asia
10 Participatory rural appraisal techniques in disenfranchised communities: a Kenyan case study	Maalim AD (2006)	East Africa
11 People, pigs and pollution – experiences with applying participatory learning and action (PLA) methodology to identify problems of pig-waste management at the village level in Fiji	Terry JP and Khatri K (2009)	Melanesia – South Pacific
12 Networking grassroots efforts to improve safety and health in informal economy workplaces in Asia	Kawakami T (2006)	East Asia
13 Chinese village women as visual anthropologists: A participatory approach to reaching policymakers	Wang C, Burris MA and Yue Ping X (1996)	East Asia
14 Adapting visual methods: action research with Kampala street children	Young L and Barrett H (2001)	East Africa
15 A contribuição da pesquisa avaliação para o processo de implementação do controle social no SUS	Batista A, Muniz JN, Neto JAF and Cotta RMM (2010)	South America
16 Worker participation in change processes in a Danish industrial setting	Rasmussen K, Glasscock D, Hansen O, Carstensen O, Jepsen J and Nielsen K (2006)	Northern Europe
17 De la invisibilidad de la situación de las policlínicas comunitarias-rurales en Uruguay, a la priorización de la salud rural como política pública	Borgia F, Gualarte A, Gabrielzyk I, Azambuja M, Soto J, Corneo M, Giménez H, Arraras M and González S (2012)	South America
18 Community concepts of poverty: an application to premium exemptions in Ghana's National Health Insurance Scheme	Aryeetey GC, Jehu-Appiah C, Kotoh AM, Spaan E, Arhinful DK, Baltussen R, van der Geest S and Agyepong IA (2013)	West Africa
19 Using participatory action research to build healthy communities	Minkler M (2000)	North America
<b>Paper for Part three: Issues &amp; challenges</b>		
20 Participatory action research: considerations for ethical review	Khanlou N and Peter E (2005)	Worldwide
<b>Paper for Part four: Evidence &amp; action</b>		
21 Best practices in the reporting of participatory action research: Embracing both the forest and the trees	Smith L, Rosenzweig L and Schmidt M (2010)	Worldwide

## Selected papers for Part one: Concepts

*Part one* presents an overview of participatory action research in health systems and in health policy and systems research. The papers selected discuss key participatory action research features and highlight the different forms adopted and their origins. They réer un lien actifconsider how participatory action research has addressed issues of power and participation in health systems and shifted control over knowledge production towards the communities affected.

### Reference and copyright permissions: Papers 1–6

The selected papers were reprinted with permission from the following sources:

#### Paper 1

Loewenson R et al. (2011) **Raising the profile of participatory action research at the 2010 Global Symposium on Health Systems Research, MEDICC Review** 13(3):35–38

<http://www.scielosp.org/pdf/medicc/v13n3/08.pdf>

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#### Paper 2

Fals Borda O (1987) **The application of participatory action-research in Latin America**, *International Sociology* 2: 329–347

<http://iss.sagepub.com/content/2/4/329>

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#### Paper 3

Falabella G (2002) **Experiencias y metodología de la investigación participativa** (*Experience and methodology in participatory research*), pages 19–32 in Durston J and Miranda F (eds) *Experiencias y metodología de la investigación participativa*, CEPAL-SERIE Políticas sociales N° 58 ECLAC-CEPAL, Santiago de Chile Comisión Económica para América Latina y el Caribe (CEPAL), marzo de 2002. Publicación de las Naciones Unidas, N° de venta: S.02.II.G.26.

<http://www.cepal.org/publicaciones/xml/4/10204/cl1715-p.pdf>

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#### Paper 4

Estacio EV and Marks DF (2010) **Critical reflections on social injustice and participatory action research: The case of the indigenous Ayta community in the Philippines**, *Procedia Social and Behavioral Sciences* 5:548–552

<http://www.sciencedirect.com/science/article/pii/S1877042810015144>

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#### Paper 5

Othieno C et al. (2009) **Use of participatory, action and research methods in enhancing awareness of mental disorders in Kariobangi, Kenya**, *International Psychiatry* 6 (1):18–19

<http://www.rcpsych.ac.uk/pdf/ipv6n1.pdf>

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#### Paper 6

Mbwili-Muleya C et al. (2008) **Consolidating processes for community – health centre partnership and accountability in Zambia**, Lusaka District Health Team and Equity Gauge Zambia, [Internet] EQUINET, Harare.

<http://www.equinet africa.org/bibl/docs/PRAequitygauge2008.pdf>

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## Selected papers for Part two: Methods

Part two deals with implementation and the papers selected provide examples of the process and methods for implementing participatory action research and the tools for gathering evidence, across a wide range of countries and contexts.

### Reference and copyright permissions: Papers 7–19

The selected papers were reprinted with permission from the following sources:

#### Paper 7

Laurell AC et al. (1992) **Participatory research on workers' health**, *Social Science & Medicine* 34(6):603–613

<http://www.sciencedirect.com/science/article/pii/027795369290188V>

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#### Paper 8

Garwick AW and Auger S (2003) **Participatory action research: the Indian Family Stories Project**, *Nursing Outlook* 51(6):261–266

<http://www.sciencedirect.com/science/article/pii/S0029655403002008>

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#### Paper 9

Inmuong U et al. (2011) **Participatory health impact assessment for the development of local government regulation on hazard control**, *Environmental Impact Assessment Review* 31(4): 412–414

<http://www.sciencedirect.com/science/article/pii/S0195925510000594>

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#### Paper 10

Maalim AD (2006) **Participatory rural appraisal techniques in disenfranchised communities: a Kenyan case study**, *International Nursing Review* 53:178–188

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#### Paper 11

Terry JP and Khatri K (2009) **People, pigs and pollution – Experiences with applying participatory learning and action (PLA) methodology to identify problems of pig-waste management at the village level in Fiji**, *Journal of Cleaner Production* 17(16):1393–1400

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#### Paper 12

Kawakami T (2006) **Networking grassroots efforts to improve safety and health in informal economy workplaces in Asia**, *Industrial Health* 44(1):42–47

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#### Paper 13

Wang C, Burris MA and Yue Ping X (1996) **Chinese village women as visual anthropologists: a participatory approach to reaching policymakers**, *Social Science & Medicine* 42(10): 1391–1400

<http://www.sciencedirect.com/science/article/pii/0277953695002871>

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#### Paper 14

Young L and Barrett H (2001) **Adapting visual methods: action research with Kampala street children**, *Area* 33(2):141–152

<http://onlinelibrary.wiley.com/doi/10.1111/1475-4762.00017/abstract>

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#### Paper 15

Batista A et al. (2010) **A contribuição da pesquisa avaliação para o processo de implementação do controle social no SUS** (*The contribution of evaluation research for the process of implementation of social control in SUS [National Health System]*), *Saúde e Sociedade* São Paulo 19(4):784–793

<http://www.scielo.br/pdf/sausoc/v19n4/06.pdf>

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#### Paper 16

Rasmussen K et al. (2006) **Worker participation in change processes in a Danish industrial setting**, *American Journal of Industrial Medicine* 49:767–779

<http://onlinelibrary.wiley.com/doi/10.1002/ajim.20350/abstract>

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#### Paper 17

Borgia F et al. (2012) **De la invisibilidad de la situación de las policlínicas comunitarias-rurales en Uruguay, a la priorización de la salud rural como política pública** (*From the invisibility of the situation of rural and community health services in Uruguay towards the prioritization of rural health as public policy*) *Saúde em Debate*, Rio de Janeiro, 36(94):421–435

<http://www.scielo.br/pdf/sdeb/v36n94/a14v36n94.pdf>

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#### Paper 18

Aryeetey GC et al. (2013) **Community concepts of poverty: an application to premium exemptions in Ghana's National Health Insurance Scheme**, *Globalization and Health* 9:12

<http://www.globalizationandhealth.com/content/pdf/1744-8603-9-12.pdf>

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#### Paper 19

Minkler M (2000) **Using participatory action research to build healthy communities**, *Public Health Report* 115(2-3):191–197

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1308710/pdf/pubhealthrep00022-0089.pdf>

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## Selected papers for Part three: Issues & challenges and Part four: Evidence & action

### Part three: Issues & challenges

Part three raises various issues in applying participatory action research methods, including facing logistics challenges, addressing data quality and validity and generalizing results. The paper selected examines the way ethical issues are addressed in doing participatory action research.

#### Reference and copyright permission:

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#### Paper 20

Khanlou N and Peter E (2005) **Participatory action research: considerations for ethical review**, *Social Science & Medicine* 60:2333–2340

<http://www.sciencedirect.com/science/article/pii/S0277953604005106>

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### Part four: Evidence & action

Part four presents options for and experiences in communicating and using evidence from participatory action research, including through learning networks. The paper selected gives guidance on reporting the knowledge generated in participatory action research in health systems and policy.

#### Reference and copyright permission:

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#### Paper 21

Smith L, Rosenzweig L and Schmidt M (2010) **Best practices in the reporting of participatory action research: embracing both the forest and the trees**, *The Counseling Psychologist* 38(8):1115–1138

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*'The Reader is a very well written and useful publication. We share the spirit of the Reader and the attempt to democratize research and make it more inclusive, by making it participatory, in local people's control, and ensuring, in particular, that the voices of the poorest people and communities are included.'*

Mirai Chatterjee, Director, Self-Employed Women's Association Social Security, India

*'It is a propitious time for participatory work to prick the anesthesia that is settling into our collective bodies. PAR projects gather up social critique and outrage, ambivalence and desire, as forms of knowledge. Inquiry is valued as oxygen for democratic sustenance ..... With innovation and a proud legacy of activist social researchers, participatory research collectives can interrupt the drip feed, engage critical questions, produce new knowledge, provoke expanded audiences, and allow us to ask as scholars, in the language of the poet Marge Piercy (1982), how can we "be of use?"'*

Michelle Fine, City University of New York

Participatory action research seeks to understand and improve the world by changing it. It transforms the role of those who usually 'participate' as the subjects of research.

Instead, those directly affected by problems become active researchers and agents of change who collectively act, produce change and create new knowledge.

