



## International Collaboration for Participatory Health Research

### Position Paper No. 1

# What is Participatory Health Research?

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## 1. Introduction

Participatory approaches to health research are increasingly drawing the attention of funders, decision makers, researchers and civil society worldwide. There is a great diversity among these approaches in terms of intention, theory, process, and outcome (Waterman et al. 2001; Ismail 2009; Whitelaw et al. 2003; Minkler & Wallerstein 2008; Rocha & Aquiar 2003). This diversity reflects the large variety of people, places, and issues involved in Participatory Health Research (PHR) in many different countries and under widely varying conditions. PHR is often viewed as being a means for achieving positive transformation in society in the interest of people's health, for example by changing the way health professionals are educated, the way health care institutions work, and the politics and policies affecting the health of society.

The International Collaboration for Participatory Health Research (ICPHR) was created in 2009 as a place to bring together what we are learning internationally about the application of participatory research approaches to address health issues (Wright et al. 2009, 2010). Through consolidating existing knowledge and reaching agreement on common terminology and principles, the ICPHR seeks to strengthen the role of PHR in intervention design and decision-making on health issues and thus to provide a means for people most affected by health problems to influence how these problems are addressed in society. This includes developing guidelines for conducting and evaluating PHR, describing which forms of theory and evidence are produced by this approach, and finding a means for conducting systematic reviews of the PHR literature in order to contribute to the body of international knowledge on health.

This paper is one contribution, from a particular set of perspectives, to the international discussion on PHR. In such an emerging and diverse field, there is no "definitive" description of this approach. Although qualitative research and PHR are distinct, each is an open-ended project which "resists attempts to impose a single, umbrella-like paradigm over the entire project." (Denzin & Lincoln 2011, p. xiii) PHR, and participatory research more generally, cannot be confined to a narrow set of epistemological principles (Fals-Borda & Rahman 1991). Part of PHR's richness and appeal is the range of paradigms, strategies of inquiry, and methods of analysis that researchers can draw upon and utilize. PHR's multiple disciplinary histories leads to constant tensions and contradictions regarding its methods, findings and interpretations. This inherent plurality is part of PHR's epistemological strength which we strive to recognize in this position paper.

This paper is a living document defining PHR, based on the experience of the members of the ICPHR and their ongoing work to synthesize what has been learned in

the context of studies conducted in various countries. It will be revised over time, reflecting the collective knowledge of the ICPHR membership. It is the product of a certain point in history and the community of people engaged in its writing who themselves live and work in politically charged spaces. What unites the members of the ICPHR is their commitment to articulating their experience with PHR and to making more visible the uniqueness of this form of research.

## 2. Participatory Health Research is a Paradigm, not a Method

We understand PHR as being a research paradigm rather than a research method. The research paradigm guides the research process.

**Participation as a research method** means that people are involved in health research in specific ways in order to improve the quality of the research. In recent years there has been a movement in some countries to increase the participation of citizens in health research by consulting them over the course of developing and implementing studies (e.g. Cropper et al. 2010; DoH 2006; DoH 1999; Institute of Medicine 2009; National Health and Medical Research Council 2002). For example, people affected by the health problem under study are consulted in advance regarding research topics and priorities (Stewart et al. 2012); they are asked to review and critique the interventions which are to be tried in the context of the research (Trivedi & Wykes 2002); or they are engaged in recruiting study participants, in distributing questionnaires, etc. In addition, there is an increasing repertoire of data collection methods to engage study participants in a more active way, as compared to traditional interviews or surveys (Van de ven 2007). These various ways of increasing the involvement of people affected by the health problem under study has led to improvements, for example, regarding recruitment, retention of participants (less loss-to-follow-up), quality of data, data interpretation, and dissemination of findings. Most of the involvement, however, has been directed by the academic researchers and funders, who define specific points where input is needed from patients and/or the general public (Boote et al, 2002; White & Verhoef, 2005). Van de ven (2007) describes how the limiting of involvement to certain points in time and to certain activities has maintained outside control over the research problem/issue as well as over the research process, despite a wide range of input from various stakeholders. Who controls the research process is now being questioned, with some researchers calling for increased control of non-academic researchers by recognizing participation as a paradigm to guide the overall research process (Abma 2006; Abma & Broerse 2010).

**PHR as a research paradigm** means that participation is the defining principle throughout the research process. A research paradigm is the set of underlying

assumptions about the world and how it should be studied which serves as the basis for defining what constitutes “good research” (cf. Guba & Lincoln 2005; Kuhn 1996). For PHR, the primary underlying assumption is that participation on the part of those whose lives or work is the subject of the study fundamentally affects all aspects of the research. The engagement of these people in the study is an end in itself and is the hallmark of PHR, recognizing the value of each person’s contribution to the co-creation of knowledge in a process that is not only practical, but also collaborative and empowering (Onwuegbuzie et al. 2009). The engagement of others within the research process can also be important, for example, policy makers who can act on the research findings and thus improve the situation of those affected by a health issue.

### **3. Participatory Health Research and Other Approaches**

We do not view PHR as being categorically “better” than other forms of research. PHR does, however, produce forms of knowledge and action which make a unique and important contribution to addressing health issues (including healthcare provision), particularly issues related to the social determinants of health and health inequalities, as will be discussed below.

### **4. Origins of Participatory Health Research**

PHR is informed by a rich variety of participatory research traditions from different countries and time periods. All of these traditions have their basis in broad social movements striving for a more democratic and inclusive society. There is a shared recognition that science is more than adherence to specific epistemological or methodological criteria, but is rather a means for generating knowledge to improve people’s lives (cf. Santos 1988). The various traditions informing PHR include: Participatory Rural Appraisal (e.g. Chambers 1981; Narayanasamy 2009); Liberationist Research approaches (e.g. Freire 1970, 1982; Fals-Borda & Rahman 1991); Action Research in organizational development (e.g. Lewin 1948; Lorau 1993); Action Research in education (e.g. Stenhouse 1975; McNiff 1992; Elliot 1991; Kemmis and McTaggart 1986; Carr & Kemmis 1986; Tripp & Wilson 2001); participatory research in the context of local, national, and international movements (e.g. People’s Health Movement 2013; Stepping Stones 2013; IPPF 2013); Lay/Community Epidemiology, Popular Epidemiology (e.g. Watterson 1995); Human Inquiry and Cooperative Inquiry (e.g. Heron 1996; Reason 1998); Appreciative Inquiry (e.g. Cooperrider and Whitney 1999; Reed 2007); Community-Based Participatory Research (e.g. Minkler & Wallertstein 2008; Israel et al. 2005); Action Science (Argyris et al. 1985); Constructivist Research (e.g. Guba & Lincoln 1989); Feminist Research (e.g. Maguire 1987; Lather

1986b); Empowerment Evaluation (e.g. Fetterman et al. 1995) and Democratic Dialogue (e.g. Gustavsen 1992).

PHR practitioners may adhere to one or more of these traditions. More commonly, they draw on several sources, adapting their approach to the particular context in which they are working.

## **5. Characteristics of Participatory Health Research**

Although there is a great diversity within PHR, the following principles are emerging as being common to many approaches (cf. Hart & Bond 1995; Waterman et al. 2001; Whitelaw et al. 2003; Israel et al. 1998, 2003; Viswanathan et al 2004; Ismail 2009; Macaulay et al. 1999; Cargo & Mercer 2008). This is not intended as the “definitive” or complete list of characteristics, but rather as an attempt to name some of the distinguishing features of participatory approaches to health research.

### **1) PHR is Participatory**

The goal of PHR is to maximize the participation of those whose life or work is the subject of the research in all stages of the research process, including the formulation of the research question and goal, the development of a research design, the selection of appropriate methods for data collection and analysis, the implementation of the research, the interpretation of the results, and the dissemination of the findings. Such participation is the core, defining principle of PHR, setting this type of research apart from other approaches in the health field.

Research is not done “on” people as passive subjects providing “data” but “with” them to provide relevant information for improving their lives. The entire research process is viewed as a partnership between stakeholders which may include academic researchers; professionals in the fields of health care, education and social welfare; members of civil society; policy makers and others. To be called participatory, the people whose life or work is the subject of the research need to actively take part in the research process. For example, where the subject of research is developing internal communication among staff in a health institution, the staff need to be involved. Where the subject of the research is improving the health of people in a neighborhood, residents of the neighborhood need to be part of the process. And where the subject of the research is the quality of services being provided by the health care system, both professionals and service users need to be engaged, as each group is directly affected by issues of quality. As stated above, the engagement of others within the research process can also be important.

Several generalized “scales” have been created to aid those conducting participatory research to identify the degree to which the various stakeholders are involved. For example, Cornwall (2008) identified six types of participation (cf. von Unger 2012b):

- **co-option** – where token representatives are chosen but have no real input or power in the research process
- **compliance** – where outsiders decide the research agenda and direct the process, with tasks assigned to participants and incentives being provided by the researchers
- **consultation** – where local opinions are asked for, but outside researchers conduct the work and decide on a course of action
- **co-operation** – where local people work together with outside researchers to determine priorities, with responsibility remaining with outsiders for directing the process
- **co-learning** – where local people and outsiders share their knowledge in order to create new understanding and work together to form action plans, with outsiders providing facilitation
- **collective action** – where local people set their own agenda and mobilize to carry out research in the absence of outside initiators and facilitators

Such scales have been complemented by models which describe participation as occurring at different levels within a system, articulating the relationship between “individual” and “organizational” participation. Smithies and Webster (1998) cite the notion of an “onion” model with layers linking: isolated individuals; community development and participation; organizational development and participation. Rifkin (1996), referring to community participation per se, distinguishes between three different models which provide a useful framework for positioning PHR (Figure 1):

Figure 1: Models of Community Participation

Approach	Model	Process
Medical	Compliance	Marginal participation
Health planning	Contribution/collaboration	Substantial participation
Community development	Community control	Structural participation

Source: Rifkin 1996.

Other authors have drawn the boundaries differently, tying participation more closely to intention. For example, Blackstock et al. (2007), making reference to concepts underpinning deliberative democracy, identify the following forms:

- **normative:** encouraging social and individual learning
- **substantive:** encouraging multiple perspectives to improve the understanding of the issues and identify solutions
- **instrumental:** reducing conflict and helping action

The ICPHR does not recommend any particular model for defining the levels of participation in a research process. The appropriateness of any given model is largely dependent on local culture and context, the available resources, and the joint decision-making process in each research team. Using a model helps researchers to be actively aware of the participatory dimensions of the study and to reflect on the purpose and expected impact of these dimensions. Whatever model is used to describe participation in the research process, the goal of PHR is to provide the opportunity for all participants to be equitably involved to the maximum degree possible throughout the research.

Attempts to maximize participation cannot be confined to simple invitations, but need to use the vast array of methods developed over the last several years to engage people in research processes. This requires an active and intensive commitment on the part of those initiating the research. Processes of engagement are at the core of PHR. PHR practitioners need to identify concrete and meaningful ways to judge the degree and adequacy of participation for those involved in each specific context and to report on the level of participation reached.

Unpacking the who, what, and how of participatory research means thinking about optimum participation in terms of what makes sense for different purposes and contexts. This has implications for specific research methods and tools which also have to be adapted to satisfy the participatory principle. The co-creative process of PHR requires facilitation and the building and maintenance of trust, the latter dependent on developing attitudes and behaviors that mirror the fundamental human values of dignity and respect. A solid groundwork needs to be laid regarding all of these matters at the onset of any research process; process maintenance and support are required to assure that this groundwork is secured throughout. This is a challenge. In many cases the potential for participation in a research process is not fulfilled. A particular problem is what Cornwall (2008) calls “functional participation,” confining community members to supporting roles with no real decision-making power over the research process. A recent systematic review of PHR has shown, for example, that participation was lowest

regarding proposal development and financial responsibility for grant funds (Salimi et al 2012).

Even in situations where there is a strong adherence to the principle of PHR as a collaborative and shared process, the outside (academic) researcher will frequently be responsible for initiating a project because of the constraints associated with funding and ethics processes (McIntyre 2008).

## **2) PHR is Locally Situated**

PHR is grounded in the reality of daily life and work in a specific place and time.

The issue being researched must be located in the social system which is likely to adopt the changes that result from the research process. This is the strength of PHR and results in the further development of local knowledge. It is this local dimension that often presents the greatest challenge to funders and policy makers as well as to those who assume that their generalized knowledge (“scientific” or “professional” knowledge, in the usual sense) is superior. The local dimension not only impacts the choice of research focus but also the research methods used, the process of learning from the research, and its impact (cf. Stoecker 2013). As a consequence, narrative accounts of the local situation (local stories) are often an important part of the participatory research process. The use of narratives closes the gap between people’s lived realities, science, and questions of policy. Narratives enhance the ability of PHR to organize spaces of collective participation (cf. Rocha & Aquiar 2003; Ledwith & Springett 2010).

The emphasis placed on the local level of knowledge and experience does not mean that PHR projects are necessarily restricted to having a local scope. Increasingly there are examples of PHR projects which mobilize a large number of people to pool their local knowledge in order to make statements about health issues at the regional, national or international level (e.g. IPPF et al. 2013; von Unger 2012a; Wright 2010; ATHENA & GCWA 2013)

## **3) PHR is a Collective Research Process**

In non-participatory forms of health research the research process is generally under the control of one or more academics who are responsible for all aspects of the study. There is usually a hierarchy among the researchers, with the Principal Investigator (PI) assuming primary responsibility. In PHR the research process is typically conducted by a group representing the various stakeholders taking part in the study. This group often includes engaged citizens, members of civil society (NGOs),

health and social welfare professionals, health organizations, academic researchers, and policy makers. Any one of these stakeholders can initiate and lead a study. The title “participatory researcher” or “co-researcher” is not reserved for the academics, but rather designates all members of the research group. The leadership role consists of facilitating a shared decision-making group process for developing, implementing, analyzing and disseminating the research (see below). Through the group process the participants become co-owners of the research and experience self-efficacy through their influence on the process. An explicit goal of the facilitation is to empower all members to engage actively in the process and thus have control over the research.

The various participants involved in the research process should represent groups who are to be impacted by the research and/or need to use the results. That is, the process that takes place is not just to benefit those immediately involved in the study, but also others whom they can reach through their networks. Whether engaged citizens, members of civil society, health and social welfare professionals, or academic researchers, all participants are urged from the beginning to consider how they can involve their constituents in the research process, at the very least through the dissemination of the results. This includes acknowledging and respecting various levels and types of participant involvement (Israel et al 2008). As McIntyre (2008) points out, for example, members of the research team may not be comfortable with, or wish to be involved with all levels of dissemination.

#### **4) PHR Projects are Collectively Owned**

Consistent with the above-named principles, the ownership of the research lies in the hands of the group conducting the study. The group needs to decide how best to report on the findings of the research in order to meet the set goals (Stoecker 2013).

#### **5) PHR aims for Transformation Through Human Agency**

As in other forms of participatory research, PHR follows the explicit goal of creating positive social change as a result of the research process for those persons whose life or work is the focus of the research. Typical research goals are: improving the health of a specific group of people; addressing the social determinants of health by improving living standards; addressing the political determinants of health by changing repressive or restrictive policy; improving the quality of services by addressing organizational issues. Actions to produce social change are embedded in the research process itself and are themselves the topic of the research (in accordance with the tenets of Action Research, more generally), or the actions to produce change directly

follow the completion of the research based on an agenda for action formulated as an outcome of the study.

Health research—including non-participatory research—is often concerned with improving the health and well-being of the general population or of a specific group of people affected by a particular health issue. PHR goes a step further to promote directly human agency for change. People are better able to act on their own behalf when they can systematically learn more about a topic of common interest and when they have become empowered to take action based on that knowledge. The learning is achieved through a critical reflexivity which enables participants to recognize their current situation and the socio-political causes of health and illness, particularly dynamics related to social exclusion, and how to be involved in finding solutions. Empowerment is promoted by people taking an active, deciding role in all aspects of the research process. PHR provides an opportunity for people to articulate and investigate systematically their strengths and to apply these to health issues of common concern (Israel et al. 2010).

In addition to learning and empowerment on the part of those participating in the research, transformations can take place in terms of concrete health indicators or social and political factors impinging on the health of those whose life or work is the subject of the study. These transformations are the result of the actions undertaken during or directly consequent to the research.

A quality criterion for PHR is supporting transformation processes which go beyond the span of the research project so as to contribute to lasting change in the interest of better health. Sustainable change is promoted, for example, by involving a broad coalition of stakeholders in the research, setting up structures for sustained learning and action as part of the research process, and providing skills training for local people to carry on the initiatives launched during the research once the project is completed.

## **6) PHR Promotes Critical Reflexivity**

Critical reflexivity means considering how power and powerlessness affect the daily lives and practice of those whose life or work is the focus of the research. In this way a critical consciousness (*conscientization*, Freire 1970) is developed among the participants. The micro-politics of everyday experience are recognized, allowing for new links between theory and practice, between “subject” and “object,” thus laying groundwork for change.

From the perspective of health and welfare professionals engaged in PHR, critical reflexivity can be compared to the *technical* and *practical* forms of reflexivity more typically found among professionals and often emphasized in other forms of health research (cf. Schön 1983; Ledwith and Springett 2010; Wright 2012).

**Technical reflexivity** refers to comparing one's practice to objectifiable, quantifiable, codified professional norms, now common in the health field. The goal is to provide the best possible quality by ensuring that professionals follow procedures. These norms are increasingly based on evidence generated in the context of academic research.

**Practical reflexivity** requires professionals to question set standards, based on their practical knowledge and experience, enabling them to do what is most effective in a specific context. Thus a systematic learning can take place, based on these adaptations. This form of reflexivity is now being encouraged in the context of quality improvement efforts, based on such concepts as Total Quality Management (e.g. Sallis 2002).

Technical and practical reflexivity maintain the role of professionals as experts who dispense their knowledge for the benefit of service users, a role which has been criticized as being paternalistic and thus encouraging dependency (Carapineiro 1993; Allen et al. 2010; Stoecker 2013). Social disadvantage is understood as a characteristic of the person seeking help which needs to be addressed by the expert.

**Critical reflexivity** requires professionals to question their roles and their knowledge based on power differentials between themselves and service users, and based on the expertise gained through life experiences and the social disadvantages faced by people without professional health qualifications. The critically reflective professional understands the expert role as one in which a partnership is formed with people seeking services for the purpose of promoting empowerment and thus to take action for their health. Health problems are seen as being caused not only by biological, but also by social factors which are often not under the control of the person seeking help. The critically reflective professional works with service users to develop not only individual but also collective strategies to address these social determinants.

From the perspective of those engaged in PHR who are not from the health or welfare professions, critical reflexivity can be described using the categories of health literacy defined by Nutbeam (2000). Typically we think of health research as benefiting people in terms of improving their *functional health literacy* and their *interactive health literacy*. **Functional health literacy** means the ability to understand the factors which

promote health as well as health risks and the knowledge needed to access help in the health care system. **Interactive health literacy** means the ability to seek out actively health information and to appropriate this information for the purpose of improving or preserving one's health. **Critical health literacy** refers to the ability to act together with others to address the social and political factors which impinge on the health of a group as a whole.

PHR may strengthen the technical and practical reflexivity of professionals and also the functional and interactive health literacy of others involved in the research. A central characteristic of PHR is, however, strengthening critical reflexivity and critical health literacy so that effective collective strategies for social change can be developed which address the social causes of health problems.

The dialogical processes at the heart of PHR can only be successful to the extent that issues of power are acknowledged and understood. Critical theory is an important foundation for reflexivity and can be brought into the arena for dialogue alongside local theories. The continual questioning of the "taken-for-granted" lies at the heart of reflexivity and thus of the knowledge creation process (Freire 1982; McIntyre 2008).

Critical reflexivity needs to be based in local culture and values. For example, Kaupapa Maori researchers have developed a tool for reflexivity based on their own non-western epistemology (Bishop 2005). It demonstrates how critical reflexivity is interwoven with a value system. The tool is used by the Maori researchers to encourage reflexivity during the research process thus ensuring that the quality of the research is maintained against the key elements of what constitutes good Maori research.

Critical reflexivity is perhaps the most challenging aspect of PHR work, but lies at the center of issues of authenticity, transparency and transferability, and an explicit values base.

## **7) PHR Produces Knowledge which is Local, Collective, Co-created, Dialogical and Diverse**

The knowledge typically produced by health research is by and for an academic audience. Often highly technical in both methodology and reporting, the knowledge can be difficult to diffuse to policy makers, practitioners, community leaders and others who could use the information to make change. This problem has received considerable attention in recent years under such headings as *knowledge translation* and *translational research*.

**The knowledge produced by PHR is typically local in scope.** As in other forms of participatory research, the people whose life or work is being studied have the opportunity to articulate their **local knowledge** (also known as indigenous or tacit knowledge) and to question and expand on that knowledge through the participatory research process. Local knowledge encompasses all that people know about the subject at hand based on their direct experience and their own empirical investigations. Local knowledge is typically passed on in the form of **local theories** which define health issues in concrete terms, identifying specific local causes and ways to address those causes (cf. Wright et al. 2010; Brito 2008). In contrast to “general scientific theories,” local theories are less abstract and offer different forms of generalizability. As Winter (2002, p. 144) puts it: “...an account of a specific situation that gets sufficiently close to its underlying structure to enable others to see potential similarities with other situations” (cf. Bassegy 2001).

The purpose of local theories is to provide a plausible explanation for a health issue in terms which are tangible and actionable. Local knowledge and local theories are often implicit and are seldom systematized or in written form. Through PHR these knowledge and theories can be subjected to collective inquiry and be harnessed to develop effective social change. The collective inquiry refines, articulates, and makes explicit local knowledge and theories so that the local people involved can systematically learn where health problems come from and how they can be remedied. A problem-solving approach is often central to the production of knowledge within PHR projects, requiring a collective (re-)construction of the topic under study. This process is summarized well by Park (2001, p. 82, referring to Gramsci 1971):

*[...] Participatory research begins with what people bring to this enterprise as everyday knowledge—their intimate familiarity with their environment, their knowledge of one another as members of a community, and their critical consciousness that their lives can change for better—and transforms that knowledge into a more organized form, turning common sense into good sense.*

**PHR promotes multiple ways of knowing, highlighting relational and reflective knowledge.** Ledwith and Springett (2010) describe theoretical, experiential, practical, emotional, and intuitive ways of knowing as being important for the PHR process. Typically, non-participatory health research is focused on theoretical ways of knowing drawn on formalized experiential knowing in the form of research studies. This theoretical way of knowing produces what Park (2001) has termed *representational knowledge*. Park’s typology includes:

- representational knowledge
- relational knowledge
- reflective knowledge

**Representational knowledge** is what is most commonly held for “scientific knowledge.” The *functional type* of representational knowledge is found in positivist approaches to social science (and in the natural sciences, more generally) and is most often associated with quantitative methods. The researcher assumes a distance from the subjects of the research, gathering quantifiable data to make probabilistic statements about associations between variables in a functional manner. The *interpretative type* of representational knowledge is based on the hermeneutic or interpretive tradition of social science research, most often associated with qualitative methods. Here the focus is on understanding a social issue in terms of the particularities of people’s lives, thus emphasizing the contextual and subjective aspects of human experience. In contrast to the functional type of representational knowledge, the interpretive type seeks a proximity to the people being studied so as to better understand their perspectives. It is also recognized that the subjectivity of the researcher affects the research process. Both types of representational knowledge produce abstract accounts (theories, models) of the phenomena being studied which represent underlying principles or dynamics.

**Relational knowledge** is based on affectivity, arising out of the emotional and intuitive levels of human experience. Relational knowledge is what is meant when we say we know someone or that we know right from wrong. This kind of knowing is key for building relationships among people and thus for collective processes of learning and action. It is also the kind of knowledge which connects people to one another and is constructed in a reciprocal way in the context of relationships. Relational knowledge is the foundation for developing an ethical sensibility based on empathy and understanding for others. PHR explicitly seeks to nurture this sensibility.

**Reflective knowledge** is the result of critical reflexivity and is characterized by a consciousness of the dynamics in society which result in privilege and social disadvantage. Knowledge about how these dynamics affect health is the basis for collective action to create change in order to address the social determinants of health.

In non-participatory research studies, including participation as a research method can assist greatly in producing representational knowledge. PHR can also produce representational knowledge. However, the unique contribution of PHR to health research is the relational and reflective knowledge produced. The collective research process dedicated to producing positive social change provides a unique

opportunity to acquire new, unexpected, and different types of knowledge about community-building processes and collective action which cannot be gained by academic researchers who are separate from the lives they are studying (cf. Blumer 1969). The relational and reflective knowledge generated is an **embodied knowledge** on the part of the participants which enables an immediate, unmitigated connection between knowledge and action.

**The knowledge produced by PHR is co-created and dialogical, incorporating the various perspectives of the participants.** The collective research process is conducted in such a way that knowledge is produced in an ongoing dialogue among the participants on all aspects of the research process. The various perspectives of the participants need to be incorporated into this dialogue. PHR, and participatory research more generally, is often misunderstood as being a consensus-oriented process in which the perspective of academic researchers should have little influence. We see the strength in PHR lying in the ability to uncover and examine different points of view, which may mean presenting a variety of perspectives throughout a study. Academic researchers involved in PHR are encouraged to bring their knowledge on health issues, research theory and research methods to the dialogue; their role needs to be reflected critically, however, to avoid undue influence on the process, particularly if they are in the facilitating role.

As soon as one moves from research “on” to research “with”, thus recognizing that stakeholders hold many different perspectives on an issue, knowledge is created through dialogue between the different perspectives and between the people involved. This is achieved by opening up communicative spaces in the research process (Kemmis 2006). The communicative spaces enable an interface between the known and the nearly known, between knowledge-in-use and tacit knowledge as yet to be useful. The participants bring together what can be known, in a spirit of shared learning. The concept of communicative space in this sense was described by Habermas (1970) who identified that the ideal place for people to come together was in a space of (p. 159) “...mutual recognition, reciprocal perspective taking, a shared willingness to consider one’s own conditions through the eyes of the stranger, and to learn from one another.”

PHR involves the recognition that knowledge is always in a process of becoming, it is never fixed. It is forever dialectic. The co-creative, collective process of knowledge generation requires facilitation so that trust can be built and maintained and attitudes and behaviors that mirror the fundamental human values of dignity, respect, mutuality, and reciprocity can be nurtured. It also means explicitly paying attention to power issues in terms of how each voice is heard, how the dialogue is encouraged, and how

joint ownership is created. This has implications for all stages of the research process, including data analysis.

## 8) PHR Strives for a Broad Impact

A key facet of PHR is its explicit intention of bringing about social change. As Wadsworth (1998, p. 7) puts it:

*Participatory action research sets out to explicitly study something in order to change and improve it. It most often arises from an unsatisfactory situation that those most affected wish to alter for the better (although it can also arise from the experience of something which works well, which provokes the desire to reproduce or expand it). However while there is a conceptual difference between the “participation” “action” and “research” elements, in its most developed state these differences begin to dissolve in practice. That is, there is not participation followed by research and then hopefully action. Instead there are countless tiny cycles of participatory reflection on action, learning about action and then new informed action which is in turn the subject of further reflection. Change does not happen at “the end”—it happens throughout. A hallmark of a genuine participatory action research process is that it may change shape and focus over time (and sometimes quite unexpectedly) as participants focus and refocus their understandings about what is “really” happening and what is really important to them.*

In PHR learning and research are not considered separate entities. Social learning (learning together and from each other) is a fundamental dimension of the PHR process and the continual cycle of “look, reflect, act” underpins the dynamics of developing a connected knowing. This means trying to understand the other person or idea through dialogue from relations of trust and empathy (Goldberger et al. 1996). Everyone learns as co-researcher to differing degrees. Ideally, the process should engage the participants in **transformative learning**, i.e., changes in the way they see the world and themselves (Freire 1970; Mezirow et al. 1990), through interactive processes which address both the personal and the collective. In turn, this generates an intention of being able to act based on the research findings, thus having a wider impact beyond the scientific community in the narrow sense. On the whole, how social change is defined is largely determined by whether the approach is pragmatic (that is, focused on issues of practical utilization) or emancipatory (where the focus is on changing the way people think and act in their world)—or an attempted combination of both (Johansson & Lindhult 2008; Mercer 2002).

The Knowledge Base project of the ICPHR is focused on working collaboratively to support the development of understandings of PHR and to define its impacts over time through a growing archive of research projects from different countries. Early work on the Knowledge Base has already demonstrated some of the difficulty authors have in recognizing and articulating impact. These include recognizing the impact of PHR on methodological rigor and capturing the longitudinal aspect of impacts that occur long after a project has been completed. The Knowledge Base will contribute to the emerging literature that suggests PHR may address aspects of health research that until now have not demonstrated much change, such as determinants of health and health inequities (Beckman et al. 2011; Bastidi et al 2010; Braun et al. 2012; Makosky Daley et al. 2010; Salimi et al. 2012).

Complementing the Knowledge Base project are systematic reviews being conducted by ICPHR members in different languages which address the issue of impact, among other topics. Evaluating the impact of PHR is challenging for a number of reasons: the research topics, methods, and study designs are heterogeneous; the extent of collaborative involvement may vary over the duration of a project and from one project to the next; and partnership activities may generate a complex array of both short- and long-term outcomes. In an extensive review of the English language literature, Jagosh et al. (2012) identified, selected, and appraised a large-variety sample of primary studies describing PHR partnerships. They used key realist review concepts to analyze and synthesize the data, using the PHR partnership as the main unit of analysis (cf. Jagosh et al. 2011). The link between the participatory research process and the outcomes in these partnerships was explained using the middle-range theory of *partnership synergy*, which demonstrates how PHR can (1) ensure culturally and logistically appropriate research; (2) enhance recruitment capacity; (3) generate professional capacity and competence in stakeholder groups; (4) result in productive conflicts followed by useful negotiation; (5) increase the quality of outputs and outcomes over time; (6) increase the sustainability of project goals beyond funded time frames and during gaps in external funding; and (7) create system changes and new unanticipated projects and activities.

### **9) PHR Produces Local Evidence Based on a Broad Understanding of Generalizability**

The primacy of the local context in PHR has implications for the generalization of the results of PHR studies.

As Greenwood and Levin (2005) argue, co-generative, context-centered knowledge requires a revision of traditional notions of generalization. Non-participatory

forms of health research are often focused on generating representational knowledge which can be used to develop standardized interventions for similar local settings. The question of scaling up from this perspective is thus one of replicating interventions on a large scale which have been shown to be effective under scientifically controlled conditions at the local level. The goal of PHR is developing interventions for a specific time and place, giving primacy to the local context. The result is the generation of **local evidence** which can be accumulated over time by local participants for the purpose of strengthening their ability to take effective action on health issues (cf. Brandão 1987; Wright et al. 2013). Transfer of interventions from one locality to the next is about understanding the contextual conditions in the new setting, how they differ from the setting in which the knowledge was produced, and reflecting on the consequences (Macauley et al. 2011). Through PHR a deep understanding of the essence of a particular situation can be gained and communicated to others who can then judge the relevance of the findings for their own situation (cf. Winter 2002). Realist review approaches are particularly promising in this regard, specifically seeking to document “what works, for whom and in what contexts” (Jagosh et al. 2011, 2012).

The issue of scaling up based on the findings of locally-based PHR has yet to be resolved at the conceptual and practical levels (Bennett & Roberts 2004; Wright et al. 2013; Salamander Trust 2013). One possible way forward is to think of each local PHR project as a case study; scaling up is then about a broad analysis of a range of case studies with the goal of identifying general patterns and theories while recognizing the uniqueness of place. This approach is being taken by the ICPHR in the context of the Knowledge Base project. Another idea which holds promise for PHR is “scaling across,” a concept from community development (Wheatley & Frieze 2011, p. 36): “Scaling across happens when people create something locally and inspire others who carry the idea home and develop it in their own unique way.”

## 10) PHR Follows Specific Validity Criteria

PHR incorporates both qualitative and quantitative methods, depending on the type of data required. The methods need to be adapted to the participatory research process which often means a deviation from the methodological standards found in non-participatory forms of health research. Important is the adherence to validity criteria specific to participatory research approaches. These include (cf. Greenwood and Levin 2005; Edwards et al. 2008; Roman and Apple 1990; Waterman et al. 2001; Dadds 2008; Sohng 1995; Reason and Bradbury 2008; Lather 1986b):

- **Participatory Validity**  
The extent to which all stakeholders are able to take an active part in the research process to the full extent possible
- **Intersubjective Validity**  
The extent to which the research is viewed as being credible and meaningful by the stakeholders from a variety of perspectives
- **Contextual Validity**  
The extent to which the research relates to the local situation
- **Catalytic Validity**  
The extent to which the research is useful in terms of presenting new possibilities for social action
- **Ethical Validity**  
The extent to which the research outcomes and the changes exerted on people by the research are sound and just
- **Empathic Validity**  
The extent to which the research has increased empathy among the participants

### 11) PHR is a Dialectical Process Characterized by Messiness

The knowledge and the action strategies generated by PHR arise out of a facilitated, collective research process. The process is characterized by a dialogue among participants with different perspectives on the subject under study. The dialogue does not necessarily result in a consensual view, but may reveal and promote several different views resulting in different ways of addressing the health issue at hand. In any case, the dialogical process intends to promote transformational learning based on a critical examination of the causes behind health and illness.

Transformational learning is made possible through a dialectical process in which participants are challenged to investigate assumptions based on their local (tacit) knowledge. Authentic dialogue makes such an investigation possible. Due to the variety of perspectives and ways of knowing found among the participants, a strict adherence to a research protocol and to methodological standards is not appropriate. The rigor in PHR lies in the extent to which the research is so facilitated as to make possible new, transformative insights which offer fresh approaches for action.

The dialectic in PHR, as with other forms of participatory research, is twofold. Typically a “spiral pattern” of investigation unfolds, in which participants reflect, plan, act and observe in several repeating cycles (cf. McNiff 1992). The actions are in a dialectical relationship with the generation of new knowledge, resulting in an ongoing development of both action and knowledge. This lends many PHR projects an iterative and recursive character defying a simple linear description of planning and implementing a research project. The second aspect of the dialectic involves a confrontation between different perspectives and ways of knowing among the participants. The wide range of ideas and perceptions creates a conflict for many participants, challenging them to articulate and to examine their assumptions about the subject of the study and about the role they play in exacerbating or alleviating a health problem. Established explanations become untenable when confronted with alternatively rationalized accounts brought to the dialogue by other participants in the research. A new synthesis needs to be achieved to account for the different points of view, resulting in new ways of seeing and acting. This is an important aspect of the rigor found in PHR.

If the dialectical tension is upheld, a “messiness” arises in the process, participants often exhibiting confusion and irritation as their assumptions are questioned. As Cook describes (2009, p. 282; cf. Law 2007):

*Hauling apart rhetoric and reframing and developing new ways forward is likely to be a variable, unstable and messy process. When participants and researchers zigzag between intuitive and analytical modes of thinking, thoughts and ideas are not immediately clear. Conditions for knowing are located where participants in research flounder and then find their way again, where tensions are held and dissipated. The ‘messy area’ is formed where participants have deconstructed well-rehearsed notions of practice and aspects of old beliefs, are aware of the dawning of the new, but as yet have not made sense of it. It is where “mutually incompatible alternatives” (Feyerabend, 1975) are debated and wrestled with and where co-labouring takes place. Co-labouring involves engaging in “...toil, distress, trouble: exertions of the faculties of the body or mind...an activity which is at times likely to be uncomfortable” (Sumara & Luce-Kapler, 1993:393). Where co-labouring takes place it is likely that confusing “messes”, incapable of resolution through the imposition of predetermined technical frameworks, will reside. This “messy area” is a forum for the exchange of perceptions and beliefs, a place of co-construction where strands of knowledge and learning are unearthed and critiqued. These strands ultimately act as catalysts for new knowing leading to development and change. It is the space for imaginative freedom and new ideas. It is a place to celebrate “The*

*importance of not always knowing what you are doing” (Atkinson and Claxton 2000). [...] The “messy area” can now be framed as a communicative space where participants delve into individual and collaborative understanding to disturb current knowing. It is a place where expert (practitioner) knowledge, experience, judgment, creativity and intuition are used to embrace multiple and new ways of seeing.*

The occurrence of messiness in this sense is a fundamental characteristic of PHR, where engaging with the mess is characterized as “...a complex process of inquiry, involving a wide range of techniques, where messy is taken to mean difficult, not careless.” (Mellor 1999). This results in a research process which is nonlinear and multi-focused and in research outcomes which cannot be characterized prior to the study. This quality makes it difficult for PHR proposals to meet the requirements of typical research calls, given the necessity of defining in advance the phases of the research project, the methods to be used, and the scope and nature of the results.

## **6. The Ethics of Participatory Health Research**

Research ethics have been formulated over the last several decades as a response to egregious violations of the human rights of people who have participated in research studies. Research codes of ethics assume non-participatory research designs, focusing on the duty of academic researchers to protect the rights of the subjects of their research.

The collective process of knowledge production characteristic of PHR and other forms of participatory research poses specific ethical challenges (cf. Flicker et al. 2007; von Unger & Narimani 2012). Most prominent are the conflicts which can arise among participants in research projects, particularly given the power and status differentials between the various stakeholders. These conflicts can revolve around the differing levels of participation and associated influence over the research process. Such conflicts can be exacerbated by issues related to funding and the distribution of resources among the stakeholders. Also, it is common that academic researchers face the challenge of balancing what they perceive as their duty to protect the non-academic partners and the non-academic partners’ right to self-determination.

The ICPHR is developing a position paper on ethical principles, based on international experience and current evolving ethical guidelines, to guide PHR practitioners in addressing the ethical issues raised in participatory research processes.

## 7. The Importance of Facilitation in Participatory Health Research

Among the roles vital to any PHR process is that of the facilitator—a person or people who act as intermediaries in the participatory research process between the various stakeholders. According to the context, facilitators may be called animateurs, conveners or mediators.

Facilitation is often assumed to be a technical skill comprised of a collection of techniques, thus overlooking the complexity and difficulty of the task. As such it has become one of the many analytic “black boxes” in the study of participatory processes. While the interests of different stakeholders, the psychology of participants or their expertise, have been exhaustively examined in academic studies and policy analyses, the process of facilitation itself has been largely ignored. By contrast the best facilitators constantly undertake such self-critical reflections in their own practice, usually in isolation from academic analysts.

Facilitators of participatory processes, including PHR, can contribute to the entrenchment of the very dominating authority that they are seeking to study and influence. This can occur, for example, through un-critical attempts to apply an off-the-shelf method of participation as if it were merely a technical procedure or research method. This is in stark contrast to a concept of facilitation as a craft. Like any craft it requires a comprehensive apprenticeship rather than a handful of brief lessons. The training of facilitators has to be sufficiently broad for PHR practitioners to know how to facilitate in a range of complex and usually highly politicized contexts (cf. Wakeford & Pimbert 2013; Wagner 2010; cf. Allen et al. 2010; McIntyre 2008).

The ICPHR seeks to contribute to a self-critical construction of better approaches to facilitation. As well as having a desire to achieve positive political goals, facilitation of PHR must be based on the do-it-yourself skills of a craftsman, drawing on tacit understandings far from the distanced stance of the conventional academic social researcher. The ICPHR is developing a position paper detailing what needs to be considered in the facilitation of PHR processes.

## 8. The Unique Contribution of Participatory Health Research to Addressing Health Issues

The strength of PHR and of participatory research, more generally, is the joining of knowledge and action for addressing issues at the local level. Whereas, social science has been criticized for focusing on problems and deficits, particularly of marginalized people, while offering no solutions; PHR works together with people most

affected by health problems, focusing on their strengths in order to find new forms of knowledge and collective action to effect positive change.

The Knowledge Base project of the ICPHR is collecting examples of PHR from around the world to define more clearly the unique contribution which PHR has made to addressing health issues and to synthesize the findings of individual studies for the purpose of generating common knowledge.

## 9. When is Participatory Health Research Appropriate?

PHR is not a one-size-fits-all approach nor is it always appropriate. Cook and Kothari (2003) talk quite persuasively about the “Tyranny of Participation,” whereby participative methods of inquiry simplify the nature of power and, thus, are in danger of encouraging a reassertion of power and social control—not only by certain individuals and groups, but also regarding particular bodies of knowledge. If we fail to see knowledge as an accumulation of norms, rituals, and practices that are embedded in power relations we fall back on dichotomies of power which do not adequately characterize the ways that knowledge is produced or the processes by which it becomes normalized. In other words, there is danger that the practice of PHR actually reinforces the negative aspects of the existing social order which it is trying to change. There are some contexts where PHR is not appropriate and may actually cause harm because of institutional practices or power structures. On the other hand, there are some contexts that are enabling. Kar, Lundstrom, and Adkins (1997) argue that the following are crucial for the application of participatory research approaches:

- a political environment characterized by democracy and decentralization
- support by local leadership for changing their institutions, by relearning and realizing the capability of laypeople and the richness of local resources
- the facilitation capacity for community-based planning and management, with sufficient participatory research practitioners to undertake this work

The ICPHR will develop over time, based on international experience, a set of guidelines to assist PHR practitioners in deciding when the use of participatory approaches to health research are appropriate and the characteristics of individuals and organizations/institutions best suited to undertaking a participatory approach to health research.

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