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Working Paper

Developing quality criteria for Participatory Health Research: An agenda for action

WZB Discussion Paper, No. SP I 2011-302

Provided in Cooperation with:
WZB Berlin Social Science Center

Suggested Citation: Springett, Jane; Wright, Michael T.; Roche, Brenda (2011) : Developing quality criteria for Participatory Health Research: An agenda for action, WZB Discussion Paper, No. SP I 2011-302, Wissenschaftszentrum Berlin für Sozialforschung (WZB), Berlin

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Developing Quality Criteria for Participatory Health Research

An Agenda for Action

discussion paper

Discussion Paper SP I 2011-302

April 2011

Wissenschaftszentrum Berlin für Sozialforschung (WZB)

Forschungsschwerpunkt:
Bildung, Arbeit und Lebenschancen

Forschungsgruppe
Public Health

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Abstract

Participatory Health Research (PHR) builds on a long and diverse history drawn from a range of disciplines, each of which have informed and developed their own understanding of what participatory research practice is. However, just as with qualitative methods ten to fifteen years ago, there is an increasing interest in setting out the fundamental principles that should drive the assessment of quality within PHR. While those using participatory research methods in health have often called for a review of quality criteria, to date there has not been anything published that undertakes the same substantive systematic attempt as found in qualitative research and evaluation. This paper starts the process of agenda setting on quality criteria by describing some key notions/issues that are core to PHR and relevant for developing steps for action, drawing together some key literature. The paper arose from the work of the International Collaboration on Participatory Health Research (ICHPR). Through consolidating existing knowledge and reaching agreement on common terminology and principles, the ICHPR seeks to strengthen the role of PHR in intervention design and decision-making on health issues. 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 community health.

Zusammenfassung

Die Partizipative Gesundheitsforschung (PG) entstand über einen längeren Zeitraum aus einer Vielfalt an Disziplinen, die zum Teil unterschiedliche Auffassungen von Partizipativer Forschung vertreten. Wie bei den qualitativen Forschungsansätzen vor ca. fünfzehn Jahren befassen sich immer mehr partizipativ forschende Wissenschaftler/innen mit der Ausformulierung von Gütekriterien für diese Form von Forschung. Mehrere Autor/inn/en haben einen Bedarf an einer systematischen Betrachtung der bereits formulierten Gütekriterien festgestellt, jedoch gibt es bis heute noch keinen Beitrag, der mit den Abhandlungen zu den Gütekriterien der qualitativen Forschung vergleichbar wäre. Dieses Manuskript stellt einen Versuch dar, aufgrund einschlägiger Literatur einen konzeptuellen Rahmen für die Diskussion über Gütekriterien auf dem Gebiet der PG aufzustellen. Es ist ein Ergebnis der Arbeit der International Collaboration on Participatory Health Research (ICHPR). Die ICHPR hat als Ziel, internationale Erfahrungen und Wissensbestände zum Thema Partizipative Gesundheitsforschung zusammenzuführen und einen Konsens über Definitionen und Kernprinzipien zu erreichen, um eine breitere Anerkennung und Anwendung dieses relativ neuen Forschungsansatzes zu fördern. Dies beinhaltet u. a. zu klären, welche Formen von Theorie und Evidenz durch PG generiert werden und nach welcher Vorgehensweise die Ergebnisse aus lokal situierten, partizipativ angelegten Studien systematisch zusammengetragen werden können, um einen Betrag zur internationalen Debatte über die sozialen Determinanten von Gesundheit zu leisten.

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"A repeated experience with (participatory research) has been the tension and contradiction between top down bureaucratic cultures and requirements, tending as they do to standardise, simplify and control, and demands generated at the local level tending as they do to be diverse and complex and to require local–level discretion."
(Chambers 1998)

Introduction

Participatory Health Research (PHR) builds on a long and diverse history drawn from a range of disciplines, each of which have informed and developed their own understanding of what participatory research practice is. However, just as with qualitative methods ten to fifteen years ago, there is an increasing interest in setting out the fundamental principles that should drive the assessment of quality within PHR. While those using participatory research methods in health have often called for a review of quality criteria, to date there has not been anything published that undertakes the same substantive systematic attempt as found in qualitative research and evaluation (for example: Popay et al. 1998; Eakin/Mykhalovskiy 2003; Hammersley 2007; Daly et al. 2007; Spencer et al. 2003; Calderón Gómez 2009). There have been a few exceptions, for example, both in the US and the UK there have been health technology assessment reports, the former focused specifically on community-based participatory research (CBPR)[1] and the latter on the broader field of action research (Viswanathan et al. 2004; Waterman et al. 2001). Within the now burgeoning literature in evaluation and research that utilises participatory research approaches, there is also a recognition that some research which calls itself participatory strays a long way from the core principles and basic philosophical assumptions, motivations, expectations, and practices that most in the field recognize. Moreover, there is evidence that "bad PHR" has done some major harm creating mistrust and participation fatigue (Bennett/Roberts 2004). This paper is aimed at initiating a discussion about quality in PHR amongst those who consider themselves participatory researchers with the view to developing an agenda for action as part of the International Collaboration on Participatory Health Research (Wright et al. 2009). It is based on a background paper that was presented at a meeting of ICPHR in Berlin in March 2010. It is not intended to provide a comprehensive systematic review of all the literature in the field. Rather it seeks to provide an initial overview of the issues and provide some pointers on what developing a framework for quality assurance would entail. It is expected that any framework produced would not be rigid, but rather serve as an aid to informed judgement—or as Marris and Rein (1974 cited in Williams et al. 2007) describe it "demonstrable rationality."

Scope

As a starting point a brief overview was undertaken of an almost bewildering number of available guidelines for PHR and participatory research, particularly in the grey literature. Some of these guidelines tend to be procedural in focus, often only elliptically addressing the underlying values and principles of participatory research. Others are concerned with

[1] Community-based participatory research is the most common name in the United States for participatory health research approaches.

developing a locally driven memorandum of agreements, whereby locally agreed values and principles are worked through and act as a local standard for ways of working. This latter course is more in keeping with the ethos of PR. The most comprehensive collection of such literature can be found on the website of the North American organization Community-Campus Partnerships for Health (CCPH) (http://www.ccph.info/), but the emphasis is largely North American. A question that the ICPHR will need to address is whether further or definitive guidelines are required and for whom and what purpose any further guidelines should serve. Is there some value of assessing existing and developing further guidelines for those conducting or wishing to conduct PHR and/or producing a set of specific guidelines for policy makers and funders in order to promote PHR? The latter route was chosen by the WHO/Euro Working Party on Evaluation of Health Promotion which produced a document for policy makers setting out core elements for appropriate approaches to evaluation (Rootman et al. 2001). Certainly there is a need for guidance to commissioners and funders of research, but there is also a need for some statement as to the institutional capacities and capabilities that are required to support PR.

This paper starts the process of agenda setting by describing some key notions/issues that are core to PHR and relevant for developing an agenda for action by drawing together some key literature. The agenda for action which it hopes to inspire is one that aims to further theorize, as well as to enhance the quality and relevance and to disseminate PHR among policymakers, funders, academia, and communities. Through consolidating existing knowledge and reaching agreement on common terminology and principles, the International Collaboration will seek to strengthen the role of PHR in intervention design and decision-making on health issues. 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 community health.

In developing such a framework for action it is important to look beyond the field of **health** sciences and draw on the experience of social work, education, geography, development studies, and the natural resource management sciences. It is also fruitful to draw on the experience of qualitative research and evaluation where there have been a number of attempts to wrestle with the issue of what counts as quality, all of which have had as their starting place questions of ontology and epistemology. With the increasing number of publications concerning user and public involvement/engagement in research, the time is ripe to explore what that means from a participatory perspective.

Issue 1: Defining PR/CBPR

The Variety of Definitions: Cultural and Historical Differences

1. "*[CBPR] is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and*

eliminate health disparities" (W.K. Kellogg Foundation Community Health Scholars Program, cited in Minkler/Wallerstein 2008).

2. *"Participatory research is defined as systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change." (Green et al. 1995).*
3. *"Community–based participatory research is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well–being through taking action, including social change" (Viswanathan et al. 2004).*

The above definitions are examples from the literature and illustrate there are a number of definitions used to describe PR for Health. In the US "community-based" most commonly proceeds the term, but elsewhere this phrase is not used. For the purposes of the ICPHR, the term *community* is not used, largely because in many languages there is no word for community in the American sense,[2] words connoting society or collective interest being more common. In the UK, for example, *public* involvement or *lay* involvement in research are the terms often used, although there is some debate as to whether the term *lay* is derogatory towards the knowledge base of those who are not professional researchers (Kerr et al. 2007). There are also differences of interpretation of who participates. While naturally this will depend on the focus of the study, some—largely "pragmatists"—interpret this to mean anyone outside of the university: viz., practitioners, decision makers, etc. within a defined geographic or political area, a population based on certain characteristics, or an entity that functions in society outside of the university (like an NGO, business, religious group, and so on). At the more "emancipatory" end of the spectrum, the focus is on the poor and marginalized within society. The other area of debate is whether explicitly to include the word "action." This also raises the spectre of history, as in some countries action research took a particular turn in the 1970s and became discredited (for example, in Germany: von Unger et al. 2007). To counteract this, in Sweden the term *interactive research* is used. However, as the definitions above show, implicit is always the notion of action for social change. It is, however, important to note that there is much action research that is not participatory (Greenwood/Levin 2006). Moreover, the boundary between research and reflective social practice can be rather fuzzy depending on what counts as research or science in a particular culture. Overall, any definition needs to recognise the variations between cultures and contexts including different strategic uses. This also means recognizing the necessity of adapting language (terminology) to changing political contexts.

Participatory Research as an Approach to Research, not a Methodology

It is fundamentally important to recognize that PR is an approach to research, rather than a technique or research method. Indeed, many writers argue that PR accepts eclectic methodologies and there are those who are reluctant to impose rigid standards on a

[2] The American use of the word "community" is the result of a unique history of immigration, civil rights, and the associated understanding how the interests of society are structured (cf. Labonte 1997).

process that is emergent, dependent on a particular set of relations and, therefore, context-bound. However, even if in evaluating any PR we are inevitably evaluating a process, it should still be possible to identify whether it measures up to a set of principles and values which has participation at its core. In doing so, it is important not to stray from the paradigmatic and ontological position underpinning PR and use terminology and norms from very different paradigmatic positions. In other words, in an effort to be seen as scientific we should not fall into the trap of using, for example, normative positivist terminology or discourse. While the language of paradigms erects the notion of opposition and segregation, which in itself is antithetical to the relational and dialogic nature of PHR, we need to be alert how the way discourse is used can reflect underlying power structures, imbalances, and values.

For example, a recent paper claimed that a review of the quantity and quality of the CBPR literature revealed a picture as varied as the projects, the researchers, and the communities involved. The authors claim that such extreme variation in methods and quality does not "generate a useful body of knowledge" (Faridi et al. 2007: 4). They argue further that standardizing the evaluation measures will enhance the scientific rigor of the research methods employed (Faridi et al. 2007). Unfortunately, there are still those within the health field for whom rigor is defined in relation to the norms of epidemiology usually meaning an RCT. This particular model of science is at odds with the ontological underpinnings of PR. It may be that what is considered a rigorous method in one interpretation of science may not be considered acceptable by the different standards (e.g., credibility) in PR. In PR, knowledge is generated through action and experimentation in context, with participatory democracy and social learning both as a method and as a goal. These are not technical dimensions but relational ones, so it is the quality of the relationships that underpins the quality of PR and any techniques that are used. Quality is not a product of the precise following of a technical method, but of maintaining a core set of values and principles that in themselves are negotiated in different contexts. Blumental (2006) gives an example of how that was done in one community partnership in the US in order to define the values to be observed in the research process. He further demonstrates that the quality of participatory research is also dependent on the skills of a co-research team. In addition to skills in research methodology in the conventional sense, there have to be skills available in a PHR team in terms of facilitation, negotiation, conflict resolution, and advocacy.

Making Explicit that PR is Based on a Particular Ontology and Epistemology

In identifying quality in PR there is much to learn from qualitative research where variations in paradigmatic and ontological positions are actively acknowledged and addressed (see Guba/Lincoln 2005). Indeed, Guba and Lincoln (op. cit.) have recently added PR to their framework concerning the key paradigmatic positions within qualitative research. The framework provides a potential structure for looking at the issues of any research approach (Appendix A) although in practice paradigms are not mutually exclusive or, for that matter, stable, as they are continuously evolving and merging, at the boundaries at least, if not at their core.

It could be argued that underpinning PHR at its core is the ontological position that there is unity between the natural and social worlds. Although the outer world is objectively given, it is subjectively represented. Humans, moreover, are an integral part of

the world and self determining. From an epistemological viewpoint, this means that social reality is not pre-given or deterministically predefined, but rather co-created relationally and through dialogue. Thus, research findings and definitions of reality are co-created through collaborative forms of inquiry. Practice and experience have primacy, and the language of the inquiry is grounded in the shared experiential context of the research. This has implications for research practice; namely, that the professional scientists and the involved "lay people" are both co-researchers and co-subjects thus redefining what constitutes a peer group. The creation of experiential, presentational, propositional, and practical knowledge[3] in the research cycle ensures the validity of the conclusions of the inquiry in terms of their own coherence in relation to the inquirers' experiences and action, while active participation ensures commitment to outcomes (Breu/Peppard 2003). Thus, it can be said that PR has a distinctive approach which contains underlying assumptions about the nature of reality, the relationship between the researcher and the researched, the relationship between facts and values, the nature of knowledge and, therefore, the appropriate methods.

Suggested Action: The ICPRH adopts a broad definition of PR which includes an outline of the key ontological and epistemological position and further theorises the epistemological and ontological basis and its implications for methodology.

Issue 2: The Core Principles and Values of PR

Given that PR for Health is an approach to research that is underpinned by a particular paradigmatic position, it is possible to argue that standards within PR are essentially defined by a set of shared core principles and values which in turn defines the quality of PR. These principles and values manifest themselves in different ways in different contexts. Moreover, in the literature there are many different ways in which these core principles and values are described, some of which are summarized below. Although described in a linear form, they are interconnected and should be viewed as a whole.

1) The Participation/Democratic Imperative

Most authors see this as the fundamental issue that sets this type of research apart from all others (Waterman et al. 2001). Research is not done "on" people as passive subjects providing "data" but "with" them to provide relevant information for improving their lives. Implicit is an aspiration towards a degree of equitable participation between the researchers and researched with researchers acting as facilitators or co-facilitators but recognising how power relations within a particular context may constrain this. Many therefore recognize that there are different degrees to which this is both possible and advisable, giving rise to a hierarchy of degrees of participation with an explicit

[3] **Experiential:** Knowledge created by a conscious being, fully aware of and grounded in the immediacy of the direct sensory environment, while mindful of the duality of our mental imagery and the real world; **presentational:** Knowledge generated by and communicated through a variety of mediums including art; **propositional:** formal theoretical, conceptual knowledge, usually encoded in language including maths; **practical:** knowledge created through action (Heron/Reason 2008).

ethical and political preference for aiming at the highest level at all stages of the research process.

For example, Cornwall (2008) identified six types of participation:

- **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 mobilise to carry out research in the absence of outside initiators and facilitators.

Such generalized "scales" have been complemented by seeing participation as occurring at different levels within a system, particularly articulating the relationship between "individual" and "organisational" participation; Smithies and Webster (1998) cite the notion of an "onion" model with layers linking: isolated individuals; community development and participation; organisational development and participation. Rifkin (1996), in referring to community participation per se, distinguishes between three different models which provide a useful framework for positioning participatory research (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), drawing on the concepts underpinning deliberative democracy, identify the following forms:

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

Baxter et al. (2001) in a paper called *Small Voices* which explores "lay" involvement in health research cite some tables for unpicking this dimension still further. These are presented in Appendix B.

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 involved requires facilitation and the building and maintenance of trust, the latter dependent on developing attitudes and behaviours that mirror the fundamental human values of dignity and respect. Fundamental groundwork has to be undertaken on all 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. Perry (cited in Cornwall 2008) talks about "functional participation" which is a strategy used in some less than ideal PHR, confining community members to supporting roles such as junior interviewers.

2) Collective, Co–created Dialogical Knowledge Incorporating Multiple Perspectives and Types of Knowing

If a participatory world view is adopted, all forms of knowledge come to the table and are valued. A number of authors define these various types of knowledge in different ways. For example, Park et al. (1993) see them as being: propositional, instrumental, and critical ways of knowing. For Ledwith and Springett (2010) they are experiential, theoretical, practical, intuitive, and emotional ways of knowing. However defined, local knowledge and professional research knowledge are given equal weight. A number of authors have problematised the tension between community or lay perspectives and the need for scientific rigor. However, this would seem to ignore the other distinctive dimension that flows from the participatory principle, namely the nature of the knowledge creation process. As soon as one moves from research "on" to research "with", thus recognizing that actors 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 the opening up of communicative spaces in the research process for this to take place (Kemmis 2006). It also 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 behaviours 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.

3) Impact beyond the Production of Academic Knowledge

A key facet of PR is its explicit intention of bringing about social change. As Wadsworth (1998) 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 par-

> ticipation 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." (Wadsworth op. cit.: 7).

Thus, in a participatory world, learning and research are not considered separate entities. Social learning (learning together and from each other) is a fundamental dimension of the PR process and the continual cyclical 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: 209). 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 (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. Nonetheless, there is some debate as to what action/social change actually means. 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) (Johansson/Lindhult 2008).

In a recent publication, Staley (2009) undertook an extensive review of the impact of public involvement in research for health and social care research covering a broad spectrum of involvement—from actively determining research questions and what is funded to peer researching in a whole range of different contexts, including clinical trials. Staley's work was commissioned by INVOLVE, the UK agency for promoting public involvement in research conducted by the National Health Service (NHS). Although not necessarily focused on PR, many of the studies reviewed potentially fall into that category. According to Davis (cited in Staley 2009: 4) "'Involvement' means an active partnership between the public and researchers in the research process, rather than using people as the 'subjects' of research. Active involvement can take the form of consultation, collaboration or user control."

Staley (op. cit.) identified several forms of impact that involvement in research had at five different levels.

– Impact on the public involved

  Public involvement has been reported to have had both positive and negative impacts on the people involved.

  The positive benefits include:

  - New skills and knowledge
  - Personal development
  - Support and friendship
  - Enjoyment and satisfaction
  - Financial rewards

  The negative impacts include:

  - Emotionally burdened
  - Overloaded with work
  - Exposed through the media

- Frustrated at the limitations of involvement

– Impact on researchers
  Public involvement has been reported to have both positive and negative impacts on researchers.
  The positive benefits include:
  - a better knowledge and understanding of the community
  - enjoyment and satisfaction
  - career benefits
  - challenges to beliefs and attitudes

  The negative impacts include:
  - higher demands on resources and a slower pace of research
  - loss of power
  - forced changes in working practice
  - challenging researchers' values and assumptions

– Impact on research participants
  Involving the public in research has also been reported to have had benefits for research participants. These include:
  - a better research process
  - helping people to feel more at ease
  - providing emotional support
  - providing access to information and services
  - offering hope and inspiration

– Impact on the wider community
  - Public involvement in research has been reported to have had a positive impact on the wider community, as it has helped to:
  - create trust and acceptance of research
  - keep projects grounded and focused on benefits for the community
  - improve relationships between communities and professionals

– Impact on community organisations
  Public involvement has been reported to have both positive and negative impacts on community organisations.
  The positive benefits include:
  - gaining knowledge
  - gaining a higher profile
  - making links with other community members
  - making a positive contribution

  The negative impacts include:
  - financial costs
  - increased demand for a service that is impossible to deliver

Staley (op. cit.) also reports having difficulty in assessing the impact of public involvement because of the limitations in the way involvement was reported in research journals (see also below).

4) Primacy of the Local Context

A further essential ingredient is that the research is grounded in the lived reality of daily life. The issue being researched must be located in the social system that is likely to adopt the changes that result from the research process. This is the strength of PR and results in the development of local theory. It is this dimension that often presents the biggest challenge to funders and decision makers as well as to those professions who automatically assume that their knowledge is superior. How do you fund something that is not predetermined by the experts? However, this dimension not only impacts the choice of research focus but also how the research is undertaken (data gathering and analysis). As a consequence, narrative accounts of the local situation, local stories, are often the starting point for participatory research projects.

The primacy of the local context also has implications for the concept of generalization in PR. Greenwood and Levin (2005) challenge the standard notion of generalization and argue that in co-generative, context centred knowledge traditional notions of generalization are turned on their head. Other forms of research are often focused on generating 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 PR is developing interventions for a specific time and place, giving primacy to the local context. 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. The issue of scaling up based on the findings of locally-based PR has yet to be resolved at the conceptual and practical levels (Bennett/Roberts 2004). A primary difficulty is taking into account an epistemological principle central to context-centred knowledge, namely, that any single case running counter to a generalization invalidates it and thus requires the generalisation to be reformulated. One possible way forward is to think of each local PR 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.

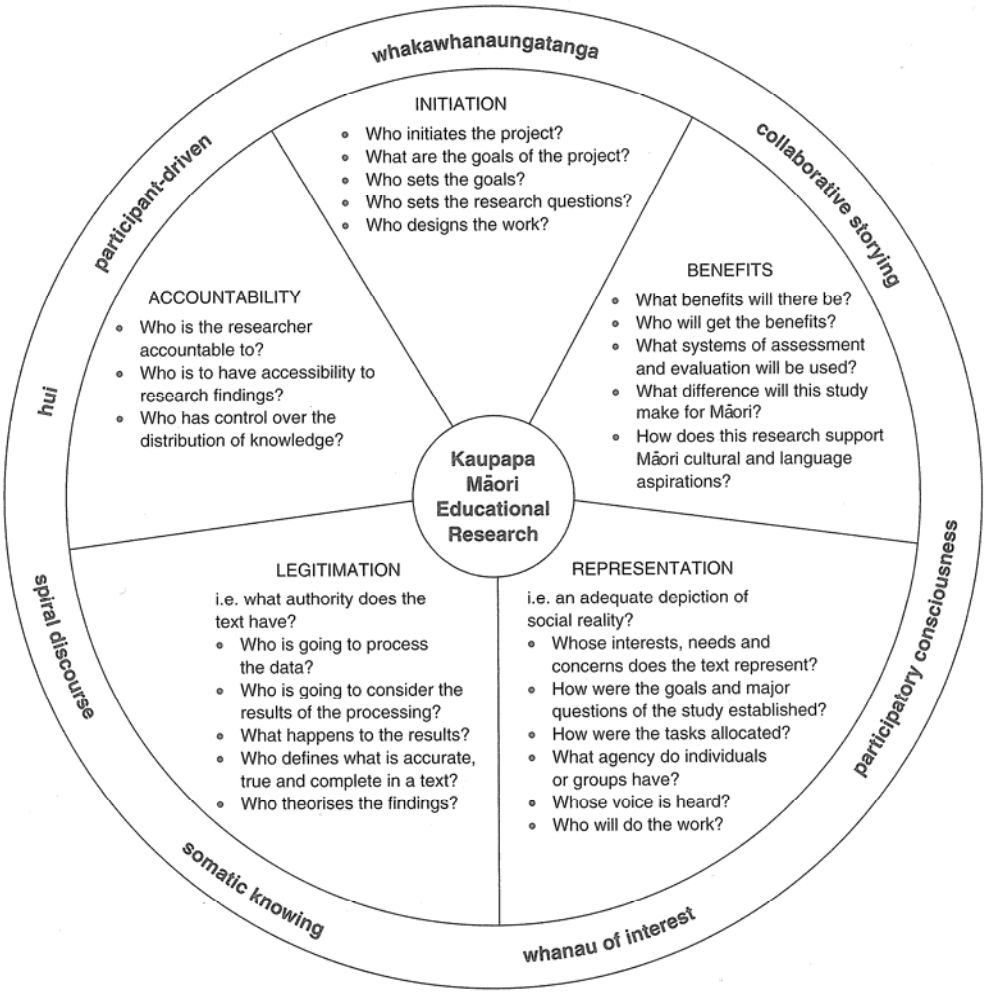
5) Reflexivity

While reflexivity has become increasingly recognized as important to qualitative research in particular, an acknowledgement of the positionality of the researcher—in participatory research critical reflexivity—is at the core of all stages of the research process. The dialogical processes at the heart of PR 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 by the professional researchers alongside local theories. The continual questioning of the "taken for granteds" lies at the heart of reflexivity and thus of the knowledge creation process. Kaupapa Maori researchers have developed a tool for reflexivity based on their own non-western epistemology. It demonstrates how interwoven with a value system critical reflexivity is when applied to issues of quality (Figure 2). The tool is used by the Maori researchers to encourage reflexivity during the research process thus ensuring the quality of the research is maintained

against the key elements of what constitutes good Maori research. Similar tools have been developed by other indigenous cultures, for example, in Canada.

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

Figure 2



Source: Bishop 2005: 131.

Suggested Action: Participatory research has principles and values at its core and these are fundamental to the research process. These principles and values are therefore crucial to any set of standards. Setting up a database, analysing that database, and seeking exemplars would further help draw a picture of what good PHR looks like in one context and another. The ICPHR should include a detailed description of the core principles and values of PR in its quality framework.

Issue 3: Validity and Credibility

In some of the articles examined for this discussion paper issues of rigour, validity, reliability, and generalisability were still commonly referenced from only a positivist perspective. This area is a particular challenge for health researchers as this form of research paradigm is particularly dominant within health sciences. Beyond the field of health sciences, the validity (or truth value) of research from a participatory perspective is derived, firstly, from the extent to which non-expert participants shape the project (authenticity of participation) and, secondly, from the extent to which the project and its findings create the conditions for action (usefulness). These considerations are given primacy over others such as the "correctness" of research procedures and the reproducibility of findings, favouring multiple voices (dialogue) over a single authoritative voice (the academic monologue).

Greenwood and Levin (2005) for example argue that validity, credibility, and reliability should be measured by the willingness of actors to act on their findings or whether the solution to a particular problem generated by the research process solves the problem. Other authors take their position from Guba and Lincoln's criteria for qualitative research namely credibility (truth value), transferability (applicability), dependability (consistency), confirmability (neutrality), and, more recently, authenticity (Edwards et al. 2008). Still others propose criteria which relate to relationships within the study. Roman and Apple (1990) propose four criteria from a feminist perspective:

- resonates with the "lived experience" of those being studied
- contributes to the understanding of participants and enables them to transform their experiences of subordination
- reduces the divide between the researchers' and "ordinary" ways of describing and understanding phenomena
- leads to the researcher's theoretical and political commitments being informed by participants' experiences.

Waterman (1998) in talking about action research distinguishes between *dialectic validity*, which recognises tensions within the field and the research process, *critical validity*, which looks at the responsibilities of the action researcher, and *reflexive validity*, which calls for the researcher to look at a range of possible sources of bias.

Marion Dadds (2008) takes validity still further and talks about *empathetic validity*, seeing it as a neglected dimension in current research practice. Empathetic validity is the potential of the research in its processes and outcomes to transform the emotional dispositions of people towards each other, such that more positive feelings are created between them in the form of greater empathy. She further distinguishes between *internal* empathetic validity (that which changes the practitioner researcher and research participants) and *external* empathetic validity (that which influences audiences with whom the practitioner research is shared). Indeed, as Spencer et al. (2003) remark, the landscape and terminology in the use of the term validity is highly contested and wide. Some conceptions relate to methods, some to the research process. They go on to suggest in terms of qualitative evaluation the following set of criteria: defensibility of the approach (the rigour of the conduct including faithful recoding of the process and a high level of reflexivity); the relationship between the researcher and the researched; the credibility of the claims; and the broader impact of the study. Sohng (1995) distinguishes between *intersubjectively valid*

knowledge, *contextually valid knowledge*, *catalytic validity* (the extent to which the research presents new possibilities for social action) and *consequential validity* (the extent to which the outcomes and changes exerted on people by the research are sound and just). Finally, Reason and Bradbury (2008) argue that in order to answer quality and validity questions one has to examine whether the experience of PR is true to its word in terms of mutuality, reciprocity, dignity, and respect. They offer the following framework for questioning the validity and quality of PR research practice:

1. **Practical outcomes:** Draw attention to pragmatic questions of practice and practising – What are the outcomes of the research? Does it work? What are the processes of inquiry? Are they authentic/life enhancing?
2. **Relationship outcomes:** How have the values of democracy been actualized in practice? What is the relationship between initiators and participants? What are the implications for infrastructure and political structures?
3. **Plural ways of knowing outcomes:** What dimensions of an extended epistemology are emphasized? Is this appropriate? What are the validity claims of different ways of knowing?
4. **Meaning and purpose outcomes:** address the issue of significance – What is worthwhile? What values have been actualized in the inquiry? At a wider level, these lead to questions of spirituality and beauty for a world truly worthy of human aspiration.

Suggested action: The working group reconceptualise validity in a way appropriate for PR, using existing concepts in the literature as a starting point.

Issue 4: Defining Quality at Each Stage of the Research Process

Currently the most well known and often cited criteria for assessing quality are those developed by Green et al. in 1995 (see Appendix B) and by Israel et al. in 2005:

- CBPR facilitates collaborative, equitable partnerships in all phases of the research.
- CBPR integrates and achieves a balance between research and action for the mutual benefit of all partners.
- CBPR recognizes community as a unit of identity.
- CBPR builds on strengths and resources within the community.
- CBPR promotes co-learning and capacity building among all partners.
- CBPR involves a long-term process and commitment.
- CBPR emphasizes local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health and disease.
- CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process.
- CBPR involves systems development through a cyclical and iterative process.

However, these criteria need revisiting in the light of the experience that has been gained over the last ten years, and a more thorough assessment of the philosophical basis to PR needs to accompany any such guidelines. In the overview of research under-

taken as background for this discussion paper, some useful frameworks in other fields have been uncovered that offer further possibilities. For example, both in terms of the process used to develop the protocol as well as regarding some of the criteria, the document by Spencer et al. (2003) for the National Centre on Social Research (UK) on Quality in Qualitative Evaluation (to be found at: http://www.civilservice.gov.uk/Assets/a_quality_framework_tcm6-7314.pdf) demonstrates how this might be undertaken as evaluation as field increasingly involves stakeholders in the evaluation and openly acknowledges the role of values in the research process.

Taking the principles previously outlined, it may be possible to develop a matrix whereby each dimension (based on one of the core principles) is set against each stage in the research process to reflect how the dimension influences that stage. For example: What are the implications for choice of research methods if a high level of participation is required? What should be given primacy at each stage of the research process or, perhaps more importantly, how do these different dimensions interact at each stage of the process and what tensions need to be addressed? Are there certain key principles that must take priority and what are the implications of that? Different authors characterize the research process in different ways. An example of how that might be undertaken is provided in Appendix D. The steps identified represent a summary of the most common conceptualizations. No attempt at this stage has been made to fill in the criteria but this may be a way forward in developing an overall framework.

An example of a comprehensive attempt to evaluate a PAR project can be found in the area of sustainability science. The authors (Blackstock et al. 2007) did an initial trawl of the literature and identified 21 different evaluative criteria of both processes and outcomes. They then selected 12 criteria against which they assessed their participatory research project using a variety of methods and data sources such as interviews, documentary analysis and field notes. A range of evaluation results from satisfactory through adequate to patchy and problematic or inadequate were revealed. The 12 criteria are shown in the following table:

Criteria for Evaluation of Participatory Research (taken from Blackstock et al. 2007)

Process

Champion/leadership: internal leadership and champions and the role of the critical outsider
Communication: the quality and flow of information to participants
Conflict Resolution: degree of conflict between participants; resolution during the process, could include quality of decision making
Influence on the process: participants' opportunity and capacity to influence (could include a resource issue)
Representation: spread of representation; perceived legitimacy, diversity of views

Context

Political, social, historical, environmental context in which the project occurs
Emergent knowledge: influence of local knowledge on the outcome of the research
Recognised impacts: perceptions of change due to participatory research
Social Learning: changes individual values and behaviour due to collaboration, in turn influencing the collective culture and norms
Transparency: both internal, whereby participants understand how decisions are made, and external, whereby observers can audit the process

Outcomes
Accountability: whether the participant's core constituencies are satisfied; also the perceived legitimacy of the process
Capacity building: developing relationships and skills so that the participants can take part in future processes

Suggested Action: The ICPHR develop in depth a structured approach to determining quality in PR, using the Spencer report as example of good practice on which to build.

Issue 5: Skills and Role of the Co-Researchers

The quality of the research in PR is dependent on the quality of the relationship between the researcher and the researched (co-researchers) and the quality of the facilitation of the process. This requires skills that are not normally provided in professional research training. Some research projects actively employ alongside the professional researcher a skilled facilitator (Leach/Wallwork 2003; Genat 2009). Equally, "lay" members need support in developing research thinking and in some case research skills. In all cases, skills in terms of group work, naming and dealing with issues of power—including giving that power up—are capacity-building necessities in this type of research.

Suggested Action: The ICPHR identify a set of criteria outlining those skills that are required over and above classic research technical skills.

Issue 6: Communicating Research to Other Parties

The phrase knowledge translation is often used to describe this part of the research process. In PRH, knowledge translation is an integral part of the process. However, within that process, how research is communicated remains a key issue. There are two dimensions to this. The first is ensuring research findings are presented in an appropriate format suitable for the co-research group, the other is setting standards for communicating research in traditional research journals and policy environments. Ideally, we should be moving towards a means by which both can be accommodated. In the case of the latter, Staley (2009) points out that quite often the nature of the research findings is decoupled from the research process because of the requirements of journals, which is often problematic. This appears to be less of a case with journals devoted to action research and CBPR, of which there are now an increasing number. O'Toole et al. (2003: 523) have proposed a process for describing PR findings in written form:

Introduction
- What is the problem being studied, including its prevalence? Are there population groups or communities that are disproportionately affected?
- Are the affected communities or population groups historically difficult to reach, poorly understood, or traditionally disenfranchised, making CBPR an appropriate methodology?

- What are the limitations or biases associated with using traditional research techniques in studying the problem? Are these limitations evident in the current body of literature?
- What are the advantages to adopting a CBPR approach to this study?
- State the explicit outcomes intended from this study in terms of (1) advancing the field of knowledge about a particular problem; (2) testing a community-based or targeted intervention; or (3) describing a process for sustaining or translating research findings, interventions, or outcomes within a community.

Methods

Setting and patients

- Describe the study population in terms of how it defines a community. How is it organized or structured? What are the points of contact and means of influence?
- How is the setting for your study or intervention relevant to the community?

Intervention

- What roles did community members, community leaders, or a community board play in each stage of the project, from design and implementation through analysis and interpretation?
- What safeguards were in place to ensure data integrity and methodologic rigor in the study design and implementation?

Analysis

- How was a community perspective incorporated into the data analysis and interpretation?

Results

- Describe your results in the context of the stated study objectives, adhering to established standards and practices for presenting scientific data.
- Report both process and outcomes measures related to an intervention, including community-level findings.
- What is happening as a result of this study within the community where the project occurred?

Discussion

- What contributions does your research bring to the field?
- What were the challenges and opportunities specific to adopting a CBPR approach that you encountered during your study?
- How were the results shared with the community?
- How are your findings generalizable to and replicable in other communities, in other settings or circumstances, or to policy makers?
- What limitations need to be considered and how should they be viewed when considering your findings?

Suggested Action: The ICPHR provide guidance on how best to report a PR project.

Issue 7: Defining When PR is not Appropriate

PR 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 participa-

tive 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 characterise the ways that knowledge is produced or the processes by which it becomes normalized. In other words, there is danger that the practice of PR reinforces the existing social order. There are some contexts where PR is not appropriate and may be actually be iatrogenic 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:

- a political environment characterised by democracy and decentralisation
- support by local leadership for changing their institutions, by relearning and realising 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

Suggested Action: The ICPHR identify indicators of where PR should not be used.

Moving Forward

PR involves a unique way of thinking about scientific inquiry as well as an attitude to the role of science in society (Cropper et al. 2007). It is context-bound, focuses on real life problems, and has democratic aspirations which place an importance on extended peer communities. Essentially, it is the ultimate real-time science in that it accepts the complex changing interconnected nature of the world and the role of the human actors that are part of that world in co-creating it. Given the differences between PR and conventional approaches to science, what is the best way forward to set out the nature of that science in a formally way that meets the needs of researchers in the field?

The UK Science Council (2009) recently defined science as: "Science is the pursuit of knowledge and understanding of the natural and social world following a systematic methodology based on evidence." In PR the process of evidence gathering and sense making is negotiated amongst the participants through dialogue and critical reflection. It actively accepts that interpretations of what counts as evidence are essentially contested and provides a process through which different meaning structures are tested using various forms of demonstrable rationality that reflect the different types of knowledge and action created. The challenge for the ICPHR is laying down that process and the issues of quality without undermining the participatory nature of the knowledge creation process itself. As a recent report by Bennett and Roberts (2004) for the Joseph Rowntree Foundation on participatory research into poverty argues, unpicking the who, the what, and the how of PR is a complex process. Therefore, a first task of the Collaboration is surely to establish a participatory process through which quality in PR can be defined, thus meeting the dialectic challenge encapsulated in the quotation at the start of this paper.

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Appendix A: Paradigms

Paradigmatic Positions in Qualitative Research

Issue	Positivism	Postpositivism	Critical Theory et al.	Constructivism	Participatory
Ontology	Naïve realism—"real" reality but apprehensible	Critical realism—"real" reality but only imperfectly and probabilistically apprehensible	Historical realism—virtual reality shaped by social, political, cultural, economic, ethnic and gender values; crystallized over time	Relativism—local and specific co-constructed realities	Participative reality—subjective-obective reality, co-created by mind and given cosmos
Epistemology	Dualist/objectivist; findings true	Modified dualist/objectivist; critical tradition/community; findings probably true	Transactional/subjectivist; value-mediated findings	Transactional/subjectivist; co-created	Critical subjectivity in participatory transaction with cosmos; extended epistemology of experiential, propositional, and practical knowing; co-created findings
Methodology	Experimental/manipulative; verification of hypotheses; chiefly quantitative methods	Modified experimental/manipulative; critical multiplism; falsification of hypotheses; may include qualitative methods	Dialogic/dialectical	Hermeneutical/dialectical	Political participation in collaborative action inquiry; primacy of the practical; use of language grounded in shared experiential context

Paradigmatic Positions in Qualitative Research continued

Issue	Positivism	Postpositivism	Critical Theory et al.	Constructivism	Participatory
Extended considerations of validity (goodness criteria)	Traditional positivist constructions of validity; rigor, internal validity, external validity, reliability, objectivity		Action stimulus (see above); social transformation, equity, social justice	Extended constructions of validity: (a) crystalline validity (Richardson); (b) authenticity criteria (Guba/Lincoln); (c) catalytic, rhizomatic, voluptuous validities (Lather); (d) relational and ethics-centered criteria (Lincoln); (e) community-centered determinations of validity	See "action" above
Voice, reflexivity, postmodern textual representations	Voice of the researcher, principally; reflexivity may be considered a problem in objectivity; textual representation unproblematic and somewhat formulaic		Voices mixed between researcher and participants	Voices mixed, with participants' voices sometimes dominant; reflexivity serious and problematic; textual representation an extended issue	Voices mixed; textual representation rarely discussed but problematic; reflexivity relies on critical subjectivity and self awareness
			Textual representation practices may be problematic—i.e., "fiction formulas" or unexamined "regimes of truth"		

Source: Guba/Lincoln 2005.

Appendix B: Guidelines

Study of Participatory Research in Health Promotion

The following guidelines can serve to appraise the extent to which research projects align with principles of participatory research.

For each guideline, check only one box. Some of the guidelines may not be applicable to the research project, in which case no boxes should be checked, or boxes labelled "Not Applicable" should be added to all the guidelines for users to check when appropriate. The categories identified by boxes for most guidelines increase in appropriateness to participatory research from top to bottom, but the most appropriate level for some projects on some guidelines might be more toward the middle or even to the upper part of the column of boxes.

Guidelines

1. Participants and the nature of their involvement:

   (a) Is the community of interest clearly described or defined?
   - ☐ No description
   - ☐ Inexplicit/general
   - ☐ Description
   - ☐ General description but explicit
   - ☐ General/detailed description
   - ☐ Detailed description

   (b) Do members of the defined community participating in the research have concern or experience with the issue?
   - ☐ No concern or experience with the issue
   - ☐ Little concern or experience with the issue
   - ☐ Moderate concern or experience with the issue
   - ☐ Much concern or experience with the issue
   - ☐ High concern or experience with the issue

   (c) Are interested members of the defined community provided opportunities to participate in the research process?
   - ☐ No opportunity to participate
   - ☐ Little opportunity to participate
   - ☐ More than one opportunity to participate
   - ☐ Several opportunities to participate
   - ☐ Many opportunities to participate

   (d) Is attention given to barriers to participation, with consideration of those who have been underrepresented in the past?
   - ☐ No attention to offsetting barriers
   - ☐ Low degree of attention to offsetting barriers
   - ☐ Moderate degree of attention to offsetting barriers
   - ☐ Moderate/high degree of attention to offsetting barriers
   - ☐ High degree of attention to offsetting barriers

(e) Has attention been given to establishing within the community an understanding of the researcher's commitment to the issue?
- ☐ No attention to the researchers' commitment
- ☐ Low attention to the researchers' commitment
- ☐ Moderate attention to the researchers' commitment
- ☐ High attention to the researchers' commitment
- ☐ Explicit agreement on the researchers' commitment

(f) Are community participants enabled to contribute their physical and/or intellectual resources to the research process?
- ☐ No enabling of contribution from participants (researchers do it all)
- ☐ Mostly researcher effort; some support for contribution from participants
- ☐ About equal contributions from participants and researcher
- ☐ Mostly resources and efforts of participants; researchers have some direct input
- ☐ Full enabling of participants' resources (researchers act only as facilitators)

2. Origin of the research question:

(a) Did the impetus for the research come from the defined community?
- ☐ Issue posed by researchers or other external bodies
- ☐ Impetus originated mainly from researchers; some input from community
- ☐ Impetus shared about equally between researchers and community
- ☐ Impetus originated mainly from community; some impetus from researchers
- ☐ Issue posed by the community

(b) Is an effort to research the issue supported by members of the defined community?
- ☐ Support for research from very few, if any, community members
- ☐ Less than half of the community supports research on this issue
- ☐ Community is roughly divided on whether the issue should be researched
- ☐ More than half of the community supports research on this issue
- ☐ Support for research from virtually all community members

3. Purpose of the research:

a) Can the research facilitate learning among community participants about individual and collective resources for self-determination?
- ☐ No provision for learning process
- ☐ Low provision for learning process
- ☐ Moderate provision for learning process
- ☐ Moderate/high provision for learning process
- ☐ High provision for learning process

(b) Can the research facilitate collaboration between community participants and resources external to the community?
- ☐ No potential for collaboration
- ☐ Low potential for collaboration
- ☐ Moderate potential for collaboration
- ☐ Moderate/high potential for collaboration
- ☐ High potential for collaboration

(c) Is the purpose of the research to empower the community to address determinants of health?
- ☐ Purpose devoid of empowerment objective
- ☐ Low priority empowerment objective
- ☐ Moderate priority empowerment objective
- ☐ Moderate/high empowerment objective
- ☐ High priority empowerment objective

(d) Does the scope of the research encompass some combination of political, social and economic determinants of health?
- ☐ No consideration of political, social or economic determinants
- ☐ Only one or two determinants are considered
- ☐ Limited consideration of combined determinants of health
- ☐ Moderate consideration of combined determinants of health
- ☐ Comprehensive consideration of combined determinants

4. Process and context-methodological implications:

(a) Does the research process apply the knowledge of community participants in the phases of planning, implementation and evaluation?
- ☐ No use of community knowledge in any phase
- ☐ Use of community knowledge in one or two phases only
- ☐ Limited use of community knowledge in all three phases
- ☐ Moderate use of community knowledge in all three phases
- ☐ Comprehensive use of community knowledge in all three phases

(b) For community participants, does the process allow for learning about research methods?
- ☐ No opportunity for learning about research
- ☐ Low opportunity for learning about research
- ☐ Moderate opportunity for learning about research
- ☐ Moderate/high opportunity for learning about research
- ☐ High opportunity for learning about research

(c) For researchers, does the process allow for learning about the community health issue?
- ☐ No opportunity for learning about the community issue
- ☐ Low opportunity for learning about the community issue
- ☐ Moderate opportunity for learning about the community issue
- ☐ Moderate/high opportunity for learning about the issue
- ☐ High opportunity for learning about the community issue

(d) Does the process allow for flexibility or change in research methods and focus, as necessary?
- ☐ Methods and focus are pre-determined; no potential for flexibility
- ☐ Mostly pre-determined methods and focus; limited flexibility about equal blend of predetermined methods and focus with flexibility
- ☐ High flexibility; some pre-determined methods and focus
- ☐ Complete flexibility; methods and focus not predetermined

(e) Are procedures in place for appraising experiences during implementation of the research?
- ☐ No procedures for appraising experiences
- ☐ Few procedures for appraising experiences
- ☐ Some procedures for appraising experiences
- ☐ Many procedures for appraising experiences
- ☐ Comprehensive procedures for appraising experiences

(f) Are community participants involved in analytic issues: interpretation, synthesis and the verification of conclusions?
- ☐ No involvement of participants in any analytic issue
- ☐ Involvement in one or two analytic issues only
- ☐ Limited involvement of participants in all three analytic issues
- ☐ Moderate involvement of participants in all three analytic issues
- ☐ Comprehensive involvement all three analytic issues

5. Opportunities to address the issue of interest:

(a) Is the potential of the defined community for individual and collective learning reflected by the research process?
- ☐ Research process not aligned with potential for learning
- ☐ Limited alignment of research process with potential for learning
- ☐ Moderate alignment of research process with potential for learning
- ☐ Moderate/high alignment of research process with potential for learning
- ☐ Comprehensive alignment of research process with potential for learning

(b) Is the potential of the defined community for action reflected by the research process?
- ☐ Research process not aligned with potential for action
- ☐ Limited alignment of research process with potential for action
- ☐ Moderate alignment of research process with potential for action
- ☐ Moderate/high alignment of research process with potential for action
- ☐ Comprehensive alignment of research process with potential for action

(c) Does the process reflect a commitment by researchers and community participants to social, individual or cultural actions consequent to the learning acquired through research?
- ☐ Commitment to action beyond data collection and analysis and writing report for funding agencies
- ☐ Low commitment to social actions based on learning through research
- ☐ Moderate commitment to social actions based on learning through research
- ☐ Moderate/high commitment to social actions based on learning through research
- ☐ Comprehensive commitment to social actions based on learning through research

6. Nature of the research outcomes:

   (a) Do community participants benefit from the research outcomes?
   - ☐ Research benefits researchers or external bodies only
   - ☐ Research benefits researchers/external bodies primarily; community benefit is secondary
   - ☐ About equal benefit of research for both researchers/external bodies and community
   - ☐ Research benefits community primarily; benefit is secondary for researchers/ external bodies
   - ☐ Explicit agreement on how the research will benefit the community

   (b) Is there attention to or an explicit agreement for acknowledging and resolving in a fair and open way any differences between researchers and community participants in the interpretation of the results?
   - ☐ No attention to or any agreement regarding interpretation issues
   - ☐ Low attention to interpretation issues
   - ☐ Moderate consideration of interpretation issues
   - ☐ High attention to interpretation issues; no explicit agreement
   - ☐ Explicit agreement on interpretation issues

   (c) Is there attention to or an explicit agreement between researchers and community participants with respect to ownership of the research data?
   - ☐ No attention to or any agreement regarding ownership issues
   - ☐ Low attention to ownership issues
   - ☐ Moderate consideration of ownership issues
   - ☐ High attention to ownership issues; no explicit agreement
   - ☐ Explicit agreement on ownership issues

   (d) Is there attention to or an explicit agreement between researchers and community participants with respect to the dissemination of the research results?
   - ☐ No attention to or any agreement regarding dissemination issues
   - ☐ Low attention to dissemination issues
   - ☐ Moderate consideration of dissemination issues
   - ☐ High attention to dissemination issues; no explicit agreement
   - ☐ Explicit agreement on dissemination issues

Source: Green et al. 1995: 43–50.

Appendix C: Ways of Measuring Participation

A Single–Dimension Framework for Analysis of the Balance of Participation in Health Research (cited in Baxter et al. 2001: 49)

Type of participation in the research process								
Professional researcher-led						Lay researcher-led		
TYPE A	TYPE B	TYPE C	TYPE D	TYPE E	TYPE F	TYPE G	TYPE H	TYPE I
Professional exclusive	Professional-led contract	Professional-led consultative	Professional-led collaborative	Collegial	Lay-led collaborative	Lay-led consultative	Lay-led contract	Lay exclusive
Characteristics of each type of participation								
Only involvement of professional research participants	Professionals 'buy in' the skills and knowledge of lay people	Professionals utilise knowledge of lay people for their own purposes	Professionals allowing the involvement of lay people in the research activities of the professional under prescribed conditions	Professional and community researchers work equally together to generate knowledge on a constraint of mutual importance	Lay people allowing the involvement of professionals in the research activities of the community under prescribed conditions	Lay people utilise the knowledge base of the professional researchers for their own purposes	Lay people 'buy in' research support from outside to address their needs	Only involvement of community-based research participants
An example of investigation where these types might occur in health research								
Research which is remote from the community. For example that which is carried out in the laboratory	Lay people are paid to take part in research activity in some way, perhaps as 'subjects'	Professionals interview lay people to access their knowledge concerning the problem or sample lay people using a survey questionnaire	Professional researchers work with lay people to draw up and jointly execute a project using methods defined by professionals	Lay people and professional researchers share a common need to identify new resources, they work together to develop a methodology, implement the research together sharing their knowledge and skills, analyse the data jointly, and share in ultimate dissemination and use	Lay people request assistance from a research institute to address a particular need they have. They work with the professionals to draw up a project using methods defined by lay people	Lay people consult professional researchers on their knowledge about the problem or need which has been generated elsewhere	Lay people request support from formal research agency to address a specific issue	Lay people generate lay knowledge of the problem through their own methods of observation and validation

Quality of Participation Matrix (cited in Baxter et al. 2001: 52)

Feature	Description	Range	Example of good practice
Relative balance of involvement of the different participants in the research	The extent to which lay people are actively involved in the research process at different stages	Contractual—consultative—collaborative—collegial	Lay people participate on an equal footing with researchers
Control	The extent to which lay people are actively involved in the decision-making about the research process at different stages	Consultation—choice of options—selection of options—decide on the selection process	Lay people, jointly with the researcher, make all decisions concerning the research
Stage of the process	The stage(s) in the research process at which the lay people are involved	Problem identification—priority setting—funding allocation—selection of research partners—research design—methods—implementation—analysis—interpretation—dissemination—use	Lay people participate in the research at all stages from problem identification through to dissemination and uptake
The quality of participation	How does that participation manifest itself?	Transparency—access to information—decision making—accountability—comprehensiveness—non-alienation	The lay people define the qualities of participation that are important to them and the standards to be achieved. The research process is then scored not only in terms of its results but the quality of the participation as well
Language	The extent to which the research is frame in the language used by the researcher or that of the user. This could be at the extreme of English researchers working within a Bengali community in an inner city, or it may be just the difference in the level of terminology used	Language of the researcher—mixture—oscillation between the two—language of the lay person	The principal language of the research is that of the lay person and the terminology used is that which the lay person is most familiar with

Quality of Participation Matrix continued

Feature	Description	Range	Example of good practice
Frame of reference	The extent to which the different knowledge systems of the researcher and lay people are used as the framework for the research	Value/knowledge system of the researcher—mixed—value/knowledge system of the lay people	The frame(s) of reference of the lay people is/are defined in advance of the research and the research is implemented within that framework but with bridges across to that of the researcher
Benefits	The type and level of benefits that accrue to the individuals and groups (researchers and lay people) involved in the research	Awareness raising—increased knowledge—increased skills—changed attitudes—direct effects—immediate positive impacts—longer-term positive impacts	The lay people leave the research with clear and distinct benefits which they define as important
Empowerment	The extent and form of empowerment that the participation enhances in the lay people. In most cases this will be something which builds on control (see above) which is mainly an internal attribute, to become something which extends after the research	No empowerment—shared power—lay peoples' empowerment after the research is significantly enhanced	The position of power within the lay person with respect to his/her help and to the health service is enhanced in a way that is sustainable after the research is completed

Quality of Participation Table (from Baxter et al. 2001: 53)

Feature of participation	Scale	Low	Medium	High
Relative balance of involvement of the different participants in the research	The degree to which lay participants perceive they are involved in the research			
Control	The level of control the lay participants feel they are able to exert during the research			
Stage of the process	The number of different stages they consider that they meaningfully participate in			
The quality of participation	Their perception of the level of quality of their participation			
Language	The extent to which the lay participants consider that the language of the research reflects that used by themselves			
Frame of reference used	The extent to which lay participants consider that the frame of reference used in the research reflects their own			
Benefits	The extent to which the lay participants derive clear and immediate benefits, as defined by themselves, from the research process			
Empowerment	The extent to which the lay participants consider that the participation in the research has given them lasting empowerment after their involvement in the research			

Appendix D: Potential Matrix

	Laying the ground work and building relationships: defining the focus and agreeing ways of working and principles	Developing the Research Questions	Deciding on Methods	Collecting Data	Analysis of Data	Exchanging interpretations and meanings	Deciding Action	Implementing Action	Evaluation
Democracy/ participation									
Co-created knowledge dialogue									
Educative and Developmental									
Issue based in local context									
Reflexivity									
Social change									

Forschungsgruppe Public Health

Public Health ist Theorie und Praxis der auf Gruppen bzw. Bevölkerungen bezogenen Maßnahmen und Strategien der Verminderung von Erkrankungs- und Sterbewahrscheinlichkeiten durch Senkung von (pathogenen) Belastungen und Förderung von (salutogenen) Ressourcen. Public Health untersucht und beeinflusst epidemiologisch fassbare Verursachungszusammenhänge und Bewältigungsmöglichkeiten. Solche Interventionen sind sowohl vor als auch nach Eintritt von Erkrankungen bzw. Behinderungen von gesundheitlichem Nutzen. Insofern erstreckt sich der Gegenstandsbereich von Public Health sowohl auf Prävention als auch auf Krankenversorgung. Wissenschaftlich ist Public Health eine Multidisziplin, politisch-praktisch sollen die daraus herleitbaren Wahrnehmungsmuster, Entscheidungskriterien und Handlungspostulate in nahezu alle gesellschaftlichen Gestaltungsbereiche und Politikfelder integriert werden. Im Vergleich zum dominanten Umgang des Medizinsystems mit gesundheitlichen Risiken und Problemen beinhaltet Public Health tiefgreifende Veränderungen der Wahrnehmungs-, Handlungs- und Steuerungslogik für die daran beteiligten Professionen und Institutionen. Die Forschungsgruppe untersucht fördernde und hemmende Bedingungen für Entstehung, Entwicklung und Wirkungen der mit Public Health intendierten sozialen Innovation.

Unter diesem Gesichtswinkel konzentrieren sich die überwiegend qualitativ ansetzenden und zum Teil international vergleichenden Arbeiten der Gruppe gegenwärtig auf Prävention und Gesundheitsförderung durch Organisationsentwicklung und Organisationslernen (z. B. in Betrieben, Stadtteilen und Institutionen) sowie durch zielgruppenspezifische Kampagnen (v. a. HIV/Aids) und auf Veränderungen im Bereich der Krankenversorgung (an den Beispielen Integrierte Versorgung und Krankenhaussteuerung).

Homepage:
http://www.wzb.eu/de/forschung/bildung-arbeit-und-lebenschancen/public-health

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