

Assessing the benefits of participatory research: a rationale for a realist review

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Abstract: Participatory research (PR) experts believe that increased community and stakeholder participation in research augments program pertinence, quality, outcome, sustainability, uptake, and transferability. There is, however, a dearth of assessments and measurement tools to demonstrate the contribution of participation in health research and interventions. One systematic review of PR, conducted for the Agency for Health Research and Quality (AHRQ), provided no conclusive evidence concerning the benefits of community participation to enhance research and health outcomes. To overcome methodological gaps and barriers of the AHRQ review, we propose to conduct a systematic realist review, which can be understood as a theory-driven qualitative review capable of capturing the often complex, diffuse and obtuse evidence concerning participation. Reviewing how PR mechanisms and contextual factors mediate and moderate outcomes, the review will generate and test hypotheses (middle-range theories) conceptualizing the benefits of participation and will portray the manner and circumstances in which participation influences outcomes. (*Global Health Promotion*, 2011; 18(2): 45–48)

Keywords: barriers to participatory research, community-based participatory research, integrative approach, participatory research, systematic review, realist review, research design

Introduction

Participatory Research (PR) is an increasingly accepted approach in health research for the added advantages it offers both researchers and end-users, which includes increasing research relevance to those participating in the process, and facilitating the translation of knowledge into practice. Indeed, endorsement of PR is growing both in North

America and internationally (1–5). Despite its increasing acceptance, two major critical reviews (6,7) and one systematic review (8) find a dearth of evidence demonstrating that positive outcomes can be attributed to the participatory process, and that PR improves health outcomes over traditional approaches (8,9). Reviewers suggest a new review is needed, especially given the increased number of completed PR studies now in the literature (6).

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Previous difficulties in PR reviews are attributed in part to diversity of research methodologies, clinical settings and groups; lack of standardized evaluation and reporting frameworks; and insufficient numbers of completed studies using a PR approach (8,10). Difficulties encountered raise three issues regarding the assessment of PR benefits: (i) how to compare PR to traditional research that does not involve stakeholders or end-users in the process; (ii) how to appraise PR; and (iii) how to examine, compare, and assess heterogeneous PR projects in a systematic way.

This commentary identifies the barriers and resulting gaps related to assessing benefits of PR through an examination of the earlier systematic review of PR in the health fields (8). Building on this previous work, we propose a realist review (11,12) as a more appropriate fit for reviewing PR.

Background

PR involves partnership and collaboration in the research process between researchers and those affected by the research. The approach seeks to generate research outcomes that are relevant and beneficial to all involved in the research, for the purpose of education, reducing health disparity, or effecting social change (6,13–16). As an umbrella term, PR is known by various names, including: action research, collaborative action research, community-based participatory research (CBPR), cooperative action research, emancipatory research, participatory action research, participatory rural appraisal, and participatory evaluation (6,7). It typically involves a set of principles for research and can include qualitative, quantitative, or mixed methods. PR takes into account the social, political, and economic contexts that guide practice and access to the resources needed for health (2) and emphasizes both generalizability and social validity (6,7,15). Principles of PR have been described by Cargo and Mercer (6) as interconnected, core elements linked to the researcher-user partnership: *mutual trust* and *respect* are important in building and maintaining the partnership, *facilitating empowerment and ownership* of the research, and in turn underpinning *sustainability*.

Examination of the AHRQ systematic review

The single major systematic review of PR in North America to date was commissioned by the US Agency for Healthcare Research and Quality IJHPE – *Global Health Promotion* Vol. 18, No. 2 2011

(AHRQ) (8). The review was limited to CBPR and addressed four key questions:

- What defines CBPR?
- How has CBPR been implemented to date with regard to the quality of research methodology and community involvement?
- What is the evidence that CBPR efforts have resulted in the intended outcomes?
- What criteria and processes should be used for review of CBPR in grant proposals?

The unit of analysis was the PR project, which sometimes spanned several publications. 30 of 60 studies retained were interventions, and were scrutinized for the influence of PR on final outcomes. Only 12 of these had been completed and evaluated at the time of the review. We suggest that the attempts to link PR to final outcomes failed due to the lack of completed studies and the lack of fit between the review methodology and the nature of PR (8). Table 1 demonstrates the challenges identified by AHRQ reviewers and resulting gaps we propose to address.

Rationale for a realist review

A different approach to assessing the benefits of PR is needed. Realist review is a theoretically-driven, qualitative approach to synthesizing qualitative, quantitative, and mixed-methods evidence from program interventions (11,12). We are using realist review to generate, test, and refine theory on the benefits of participation using the empirical evidence of completed PR projects. This approach is appropriate for assessing PR, as it provides a framework to examine not only final outcomes, but all the intermediate effects that participation generates, which, we hypothesize, may ultimately lead to enhanced final outcomes. While systematic reviews of experimental studies provide evidence for practitioners regarding *'what works'*, a realist review method opens a window on *how, for whom, and in what circumstances* does it work (12).

An initial set of theories or hypotheses pertaining to PR will be gleaned from the literature. They will then be examined using a realist mode of analysis involving the concepts of *context, mechanism, and outcome*. Although these concepts have long histories in the health and social science literature, here they are defined in terms of their usefulness for programme theory testing. Programme context

Table 1. Summary of gaps and barriers in previous reviews, and proposed solutions

<i>Barriers</i>	<i>Gaps</i>	<i>Proposed Solutions</i>
1. Lack of completed studies (and restricted to CBPR*)	Study authors were not consulted	More completed studies now exist; we will consult authors to confirm complete sets of articles
2. Lack of consensus on the definition of PR** in the conceptual literature	Studies of questionable PR** quality were included	We will use criteria from recent PR** guidelines (13) and a model relating to underlying values and drivers in PR** (6)
3. Diversity of studies presents difficulty developing an analytic framework	Many analytic frameworks were based on a linear model of research steps and did not account for iterative aspects of participation or partnership building	We will base the analytic framework on hypothesis testing (rather than research steps) in order to account for both participation and research
4. Difficulty assessing research quality due to the diversity of studies	a. Research quality was assessed hierarchically with experimental methods at the top b. Mixed methods were not accounted for	Our units of analysis will be a series of testable hypotheses (middle-range theories) to which evidence from quantitative, qualitative and mixed methods research will be equally applicable (11)
5. Difficulty linking research quality to the quality of participatory elements	Separate appraisal scores for research quality and quality of participatory elements failed to indicate the relation between them	We will take an integrative approach based on activities that connect contexts, mechanisms, and outcomes to participation (6,14)
6. Difficulty attributing research outcomes to participation	a. Based on an assumption that a comparison of PR** to traditional research is necessary b. Based on an assumption that participation is instrumental to research	We will use an integrative approach to generate and test middle-range theories on multiple conceptualizations of PR** benefits (6)

* CBPR = Community-based participatory research; **PR = Participatory research.

generally refers to aspects of the background, people and research setting that moderate outcomes. Program mechanism usually refers to the mediating variables in the change process, but here refers more specifically to the resources offered by the program and the reasoning of the participants who choose or choose not to participate. Outcomes refer to expected or unexpected intermediate (mediating) and final outcomes. Within this framework, we will demonstrate how programmes can alter their contexts during implementation and how altered contexts change the course of programme delivery. Through an iterative and inductive approach to theory building and context-mechanism-outcome configuring, our aim is to confirm or refute our program theories

that conceptualize the benefits of PR. Our use of the realist approach will assist us in conceptualizing the theories, contexts, mechanisms, outcomes, and benefits, which are perceived differently among the various stakeholders in PR. By using an empirically based approach to theory development, our understanding of what constitutes the various components of PR programmes will be shaped by what emerges in our systematic review of the literature.

This realist review is being undertaken in a participatory manner by partnering with decision-makers in four key areas where the knowledge produced by the study is valuable: funding agencies, public health agencies, institutional review boards, and communities. These partners, involved from

the outset in defining the scope of the project, are well-positioned and committed to reviewing major decisions made throughout the review. Joint decision-making occurs across all stages of research, involving finalising the research questions and developing the identification, selection, and appraisal tools. Partners will also review the findings and, most importantly, bring the results into their organizations and networks, which will enable the translation of knowledge generated into practice.

Conclusion

The systematic realist review of the benefits of PR, described earlier, will allow us to address the gaps and barriers identified from the previous AHRQ review. This approach is to study PR projects from an integrative perspective that takes into account and links underlying values and processes, contexts, mechanisms, and outcomes and to examine research and participatory elements together. We then will be able to develop a working model of benefits of PR, drawing on literature across disciplines and applying it to a wide variety of studies in the health fields.

One of the main difficulties noted by AHRQ reviewers concerned the lack of a standard reporting format for PR studies that both made the review process difficult and could lead to lower quality ratings of PR articles. Our approach may contribute the development of a reporting model for future PR projects.

This review is further strengthened by using a participatory approach and partnering with key end-users throughout the process. The goals are to improve reviews of PR grant applications; develop understanding in public health agencies and communities of how a PR approach relates to outcomes; guide community-researcher partnerships; and integrate results into ethics review guidelines for the assessment of research proposals. In targeting these four key areas we aspire to improve the understanding of how, when, and in what contexts PR provides benefits research and health outcomes.

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References

1. Green L. The Prevention Research Centers as models of practice-based evidence. *Am J Prev Med.* 2007; 33: S6–S8.
2. O’Fallon LR, Deary A. Community-based participatory research as a tool to advance environmental health sciences. *Environ Health Perspect.* 2002; 110(S2): 155–159.
3. Minkler M, Wallerstein N. *Community-based participatory research for health.* San Francisco, CA: Jossey-Bass; 2003.
4. *The future of the public’s health in the 21st century.* Washington: National Academies Press; 2002.
5. World Health Organization. Indigenous peoples & participatory health research. [Internet]. Available from: http://www.who.int/ethics/indigenous_peoples/en/index.html
6. Cargo M, Mercer SL. The value and challenges of participatory research: strengthening its practice. *Annu Rev Public Health.* 2008; 29(1): 325–350.
7. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health.* 1998; 19: 173–202.
8. Viswanathan M et al. Community-based participatory research: assessing the evidence. Rockville, MD: Agency for Healthcare Research and Quality; 2004.
9. Arble B, Moberg DP. Participatory research in development of public health interventions. *Brief Report.* 2006; 1(6): 1–4.
10. O’Toole TP, Aaron KF, Chin MH, Horowitz C, Tyson F. Community-based participatory research opportunities, challenges, and the need for a common language. *J Gen Intern Med.* 2003; 18(7): 592–594.
11. Pawson R. *Evidence-based policy: a realist perspective.* London: SAGE; 2006.
12. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review: a new method of systematic review designed for complex policy interventions. *J Health Serv Res Policy.* 2005; 10: 21–34.
13. Mercer SL et al. Appendix C: Reliability-tested guidelines for assessing PR projects. In: Minkler M, Wallerstein N (eds). *Community-based participatory research for health: from practice to outcomes*, 2nd ed. San Francisco, CA: Jossey-Bass; 2008. pp. 407–18.
14. Lantz P, Israel BA, Schulz AJ, Reyes A. Community-based participatory research: rationale and relevance for social epidemiology. In: Oakes JM, Turner J, editors. *Methods for social epidemiology.* San Francisco: Jossey-Bass Press; 2006.
15. Macaulay AC et al. Participatory research maximises community and lay involvement. *Br Med J.* 1999; 319(7212): 774–778.
16. Israel BA et al. Community-based participatory research: lessons learned from the Centers for Children’s Environmental Health and Disease Prevention Research. *Environ Health Perspect.* 2005; 113(10): 1463–1471.