

*A Realist Review for Health Research and Practice*

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## **Uncovering the Benefits of Participatory Research: Implications of a Realist Review for Health Research and Practice**

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## **Abstract**

**Context:** Participatory research (PR) is the co-construction of research through partnerships between researchers and people affected by, and/or responsible for action on, the issues under study. Evaluating the benefits of PR is challenging for a number of reasons: the research topics, methods, and study designs are heterogeneous; the extent of collaborative involvement may vary over the duration of a project and from one project to the next; and partnership activities may generate a complex array of both short- and long-term outcomes.

**Methods:** Our review team consisted of a collaboration among researchers and decision makers in public health, research funding, ethics review, and community-engaged scholarship. We identified, selected, and appraised a large-variety sample of primary studies describing PR partnerships, and in each stage, two team members independently reviewed and coded the literature. We used key realist review concepts (middle-range theory, demi-regularity, and context-mechanism-outcome configurations [CMO]) to analyze and synthesize the data, using the PR partnership as the main unit of analysis.

**Findings:** From 7,167 abstracts and 591 full-text papers, we distilled for synthesis a final sample of twenty-three PR partnerships described in 276 publications. The link between process and outcome in these partnerships was best explained using the middle-range theory of partnership synergy, which demonstrates how PR can (1) ensure culturally and logistically appropriate research, (2) enhance recruitment capacity, (3) generate professional capacity and competence in stakeholder groups, (4) result in productive conflicts followed by useful negotiation, (5) increase the quality of outputs and outcomes over time, (6) increase the sustainability of project goals beyond funded time frames and during gaps in external funding, and (7) create system changes and new unanticipated projects and activities. Negative examples illustrated why these outcomes were not a guaranteed product of PR partnerships but were contingent on key aspects of context.

**Conclusions:** We used a realist approach to embrace the heterogeneity and complexity of the PR literature. This theory-driven synthesis identified mechanisms by which PR may add value to the research process. Using the middle-range theory of partnership synergy, our review confirmed findings from previous PR reviews, documented and explained some negative outcomes, and generated new insights into the benefits of PR regarding conflicts and negotiation between stakeholders, program sustainability and advancement, unanticipated project activity, and the generation of systemic change.

**Key Words:** Participatory research, action research realist review, systematic review, partnership synergy theory, community-based participatory research

Participatory Research (PR) is the co-construction of research between researchers and people affected by the issues under study (e.g., patients, community members, community health professionals, representatives of community-based organizations) and/or decision makers who apply research findings (e.g., health managers, policymakers, community leaders). For health intervention research, proponents argue that PR strengthens relations between the community and academia; ensures the relevancy of research questions; increases the capacity of data collection, analysis, and interpretation; reduces the “iatrogenic” effects of research; and enhances program recruitment, sustainability, and extension (\*Cargo and Mercer 2008; Israel et al. \*1998, \*2005; \*Macaulay et al. 1998; \*O’Fallon and Dearry 2002). PR is believed to increase communities’ capacity to identify and solve their problems (\*Gaventa and Cornwall 2006; \*Macaulay et al. 1999) and decision makers’ and service providers’ ability to mobilize resources, improve policies, and enhance professional practices (\*Minkler and Wallerstein 2008). Previous reviews sought to understand PR and provide practical recommendations (\*Cargo and Mercer 2008; \*Green et al. 1995; \*Ismail 2009; \*Israel et al. 1998; \*Trickett and Ryerson Espino 2004; \*Waterman et al. 2001) and to assess the value of PR to research goals, health status, and systems change (\*Arble and Moberg 2006; \*Boote, Telford, and Cooper 2002; \*Gaventa and Barrett 2010; \*Kreuter, Lezin, and Young 2000; \*Roussos and Fawcett 2000; \*Viswanathan et al. 2004). Nonetheless, the assessment of outcomes remains weak (\*Berkowitz 2001; \*Gaventa and Barrett 2010; \*Viswanathan et al. 2004; \*Wallerstein et al. 2008), partly because the methodologies used have generally failed to embrace the complexity of programs or address mechanisms of change (\*Macaulay et al. 2011).

The main challenge in evaluating PR is that it is, by nature, a research *approach* that can be applied to an array of interventions encompassing a multitude of research paradigms, methodologies, and methods. This requires distinguishing analytically between the benefits of co-governance for research processes and the benefits of the research program itself (i.e., the research's health change goals). Isolating these two influences at an empirical level makes it difficult to attribute outcomes to the participatory process or some other contextual or design features. To handle such complexity, we chose a realist approach (\*Pawson 2006) because it provides a rationale and tools for synthesizing complex, difficult-to-interpret evidence from community-based programs. A realist review differs from empirically focused qualitative or quantitative methods in a number of ways, including its theory-driven and abductive (informed-intuitive) approach to understanding context, mechanism, and outcome (CMO) configurations. Using this method, our synthesis concentrated on the impact of co-governance on research processes and outcomes. We synthesized qualitative and quantitative research outcomes pertaining to the health change goals of PR partnerships only when (and to the extent that) such evidence could be clearly linked to participatory processes.

Our three research questions were revisited during the review and were updated as the review parameters were shaped. The final questions were as follows:

1. What benefits and/or constraints emerge from the collaborative undertaking of health-related research by researchers and those affected by the issues under study and/or those who would apply research results?
2. How can the collaborative research process be theorized and evaluated?
3. How do variations in the program's context and mechanisms influence the process and outcomes of collaborative health intervention research?

## **Methods**

The research team was made up of a core team at McGill University (A.C. Macaulay [ACM], J. Jagosh [JJ], P. Pluye [PP], J. Salsberg [JS], J. Henderson [JH], P.L. Bush [PLB], and E. Sirett [ES]) as well as an international network of researchers (G. Wong [GW], M. Cargo [MC], T. Greenhalgh [TG], C.P. Herbert [CPH], and L.W. Green[LWG]) and six decision-making partners from granting agencies, public health organizations, an ethics board, and a community-engaged scholarship organization. The first stages of the review involved filtering and retaining a data set from the published PR literature using a series of identification, selection, and appraisal steps. Our chosen unit of analysis was partnerships—that is, coalitions of academic and community stakeholders with equitable co-governing powers who planned, implemented, and evaluated PR health interventions. Each stage of review involved at least two independent reviewers and followed a systematic, auditable coding and retention procedure. We identified 7,167 abstracts from the literature and selected 591 full-text papers. At the end of the selection, we retained 83 partnerships and contacted the lead authors from these partnerships to make sure that we had a comprehensive set of documents for each study. Thirty-nine authors responded to complete the sets for their respective partnerships. After passing the publications through an appraisal process, a final sample of studies suitable for realist review remained: 23 partnerships, collectively composed of 276 documents, including peer-reviewed and non-peer-reviewed publications and websites that reported on empirical research, activity descriptions, and authors' reflections). The partnerships included were those describing high levels of participation by nonacademic stakeholders. This meant that we retained only those partnerships demonstrating that all partners (1) identified or set the research questions; (2) set the methodology, collected data, or analyzed the data; and (3) used or disseminated the research findings (this requirement

was loosely applied after consulting our co-investigators with expertise in PR, as it was felt that publication often preceded use and that community stakeholder participation in dissemination is often not described). Please see our protocol study paper for further information about our identification, selection, and appraisal tools (\*Jagosh et al. 2011). We found evidence of PR's impact by using the realist concepts of middle-range theory, context-mechanism-outcome configurations (CMO), and demi-regularity, which are described in box 1.

The synthesis was carried out in a number of iterative steps (\*Jagosh 2011), all of which were led by J. Jagosh, who has fifteen years' experience in qualitative research and a doctorate in communication studies. The steps were overseen by the larger team through consensus-building meetings, phone calls, and email discussions (thirteen key consensus-building meetings were held between October 2009 and May 2011). First, we extracted data from all documents that described how the co-governance of research led to certain outcomes. These outcomes had to do with either the process of building research or the research products and goals reached. These data were then organized into themes, representing semipredictable patterns occurring in the data (referred to as demi-regularities; see box 1). Having gained insight into the PR outcomes from this thematic organization, we mapped the partnerships visually in order to understand these outcomes in the context of the chronology of partnership events and processes and to ensure that we did not miss any data. The maps provided a picture of the scope and accomplishments of each partnership and enabled us to better understand how various outcomes of co-governance within a single partnership were interrelated. The data depicting outcomes of co-governance were then articulated in terms of context-mechanism-outcome (CMO) configurations and embedded in these maps. After the core team members reviewed, refined, and approved the maps, the CMO configurations were organized according to the list of demi-regularities and disseminated to the

wider team and decision-making partners for their approval. From that process, our original list of demi-regularities were refined and expanded. Finally, we applied our middle-range theory (discussed later) to the synthesis, which further refined our understanding of the demi-regularity and CMO synthesis. The final synthesis reported here is a subset of a much larger (seventy-page) unpublished synthesis, from which we chose the clearest and most relevant examples for publication. To explain the PR outcomes, each CMO is accompanied by a referenced quotation from the data.

### **Box 1 - Definition of Terms Used in Realist Reviews**

**Middle-range theory (MRT):** MRT is an implicit or explicit explanatory theory that can be used to assess programs and interventions. “Middle-range” means that it can be tested with the observable data and is not abstract to the point of addressing larger social or cultural forces (i.e., grand theories).

**Context-mechanism-outcome (CMO) configurations:** CMO configuring is a heuristic used to generate causative explanations pertaining to the data. The process draws out and reflects on the relationship of context, mechanism, and outcome of interest in a particular program. A CMO configuration may pertain to either the whole program or only certain aspects. One CMO may be embedded in another or configured in a series (in which the outcome of one CMO becomes the context for the next in the chain of implementation steps). Configuring CMOs is a basis for generating and/or refining the theory that becomes the final product of the review. A simple example of a CMO configuration is as follows:

A community experiences a high level of unemployment to which an employment training program is offered (context). But the program has low enrollment and attrition (outcome). The reason is that people have difficulty getting to the venue, owing to a lack of public transportation (mechanism).

**Context:** Context often pertains to the “backdrop” of programs and research. For example, in our work it pertains to the conditions connected to the development of research partnerships. As these conditions change over time, the context may reflect aspects of those changes while the program is implemented. Examples of context include cultural norms and history of the community in which a program is implemented, the nature and scope of existing social networks, or built program infrastructure. They can also be trust-building processes, geographic location

effects, funding sources, opportunities, or constraints. Context can be broadly understood as any condition that triggers and/or modifies the behavior of a mechanism.

**Mechanism:** A mechanism is the generative force that leads to outcomes. It often but not always denotes the reasoning (cognitive or emotional) of the various actors in relation to the work, challenges, and successes of the partnership. Mechanisms are linked to, but not synonymous with, the program’s strategies (e.g., a strategy may be a rational plan, but a mechanism involves the participants’ display of responses to the availability of incentives or other resources). Identifying the mechanisms advances the synthesis beyond describing “what happened” to theorizing “why it happened, for whom, and under what circumstances.”

**Outcomes:** Outcomes are either intended or unintended and can be proximal, intermediate, or final. Examples of PR outcomes are greater empowerment, participation, enrollment, education, knowledge, development of program infrastructure, and enhanced research processes. Examples of intervention outcomes are improved health status, more use of health services, and enhanced research results.

**Demi-regularity:** Demi-regularity means semipredictable patterns or pathways of program functioning. The term was coined by Lawson (\*1997), who argued that human choice or agency manifests in a semipredictable manner—“semi” because variations in patterns of behavior can be attributed partly to contextual differences from one setting to another.

### **Middle-Range Theory: Partnership Synergy**

Central to any realist synthesis is developing and refining candidate theories that correspond to the given area of investigation. Often, theory is incorporated at the beginning of the review and informs the development of the protocol (\*Pawson 2006). For this review, we searched for candidate middle-range theories at the outset, but because of the sample’s heterogeneity, we did not determine until after the identification, selection, and appraisal stages were complete which theory would be best applied. Selecting the appropriate theory was thus a process that we repeated as we moved through the review stages. We searched the literature extensively and examined writings on, for example, capacity building (\*Goodman et al. 1998), critical

consciousness (\*Freire 1970), health promotion (\*Green et al. 1995), social capital (\*Coleman 1988), participation (\*Green 1986), and management (\*Hibbert, Huxham, and Ring 2008).

During our synthesis, we reviewed and chose the theory of “partnership synergy” as our middle-range theory for its applicability to our heterogeneous data set and utility in conceiving PR outcomes. Lasker, Weiss, and Miller (\*2001, 184) defined *synergy* as combining the perspectives, resources, and skills of a group of people to “create something new and valuable together—a whole that is greater than the sum of its individual parts.” Applied to participatory health interventions, the theory holds that multiple stakeholder collaboration creates or enhances research outcomes beyond what could be achieved by a single person or organization working under similar conditions. Using this theoretical concept, we hypothesized that equitable partnerships with the stakeholders’ participation throughout the project succeeds largely through synergy. However, partnerships are not, de facto, synergistic and can at times be antithetical to synergistic exchange, especially with multiple partners in coalitions (\*Green 2000; \*Jordan 2003; \*Kothari and Cooke 2001). In addition, synergy increases with the *convergence* of complementary or blended perspectives through the alignment of values and goals as co-governing members work together. This reveals what we see as the main mechanism of participation: PR stakeholders’ recognizing and valuing the collective knowledge, resources, relationships, and capacity through the alignment of purpose, values, and goals. Once established, such an alignment becomes a feature of the research context in which partnerships operate. Through the use of partnership synergy as a middle-range theory, we tested three broadly generalizable hypotheses concerning the potential benefits of PR:

Hypothesis A: Contextual factors existing before the partnership was formed partially determine the extent to which PR can enhance research outcomes.

Hypothesis B: The synergy generated through multistakeholder collaboration, bringing diversity of perspective and skills, advances the research capacity beyond what could be achieved by a single stakeholder group working toward the same goals.

Hypothesis C: Partnership synergy has cumulative effects (i.e., builds momentum, strength, mutual trust, and understanding) over time, so that a PR outcome at one stage of research will influence subsequent stages.

## **Findings**

Regarding hypothesis A, the evidence from the published literature was too varied to observe consistent links between the contextual factors existing before partnership formation and the PR outcomes. Thus the findings reported here correspond to hypotheses B and C. Boxes 2 and 3 list the demi-regularities and subcategories that we identified as connecting the data to our middle-range theory and hypotheses. These lists contain the evidence we saw recurring in the twenty-three partnerships. In the next sections, we offer examples from the data that present CMO configurations pertaining to each of the demi-regularities. In each of the following subsections, although the findings are illustrated with only a single example, other examples of each were evident in our data set. Appendix 1 provides additional information about the twenty-three partnerships used in the synthesis.

**Box 2 - Demi-Regularities Pertaining to What PR Synergy Generates (Supporting Hypothesis B) and How It Accumulates (Supporting Hypothesis C)**

Demi-regularity 1 (Hypothesis B)

PR generates culturally and logistically appropriate research characteristics related to

- Shaping the scope and direction of research.
- Developing program and research protocols.
- Implementing program and research protocols.
- Interpreting and disseminating research findings.

Demi-regularity 2 (Hypothesis B)

PR generates capacity to recruit

- Community members to the advisory board.
- Community members for implementation (specifically for lay health worker programs).
- Community members as recipients of programs (intervention enrollment).

Demi-regularity 3 (Hypothesis B)

PR generates the capacity of

- The community partners.
- The research partners.

Demi-regularity 4 (Hypothesis B)

PR generates disagreements between the co-governing stakeholders during decision-making processes, resulting in both

- Positive outcomes for subsequent programming.
- Negative outcomes for subsequent programming.

Demi-regularity 5 (Hypothesis C)

PR synergy accumulates in cases of repeated successful outcomes in partnering, thus increasing the quality of outputs and outcomes over time.

Demi-regularity 6 (hypothesis C)

Partnership synergy accumulates capacity to sustain project goals beyond funded time frames and during gaps in external funding.

Demi-regularity 7 (hypothesis C)

PR generates systemic changes and new unanticipated projects and activity.

*Culturally Appropriate and Logistically Sound Research*

Synergy created in partnerships tended to generate research that was both culturally appropriate to the target group(s) and logistically realistic and feasible, taking account of the practical challenges of conducting research in community settings.

*Shaping the Scope and Direction of Research.* Partnering typically shaped the scope and direction of the research to areas deemed relevant by all parties. For example, when deciding on a research topic, Seattle Partners for Healthy Communities gave significant control to community partners. Consensus building created a community-relevant research agenda and also built trust among the stakeholders:

After 2 years of committee work, staff reviews of current literature, and group discussions that drew on board members' own experiences in health promotion and community change processes, the Community Board agreed that a focus on the "social determinants of health" captured their broader concerns with the multiple factors that affect the well-being of communities. (\*Eisinger and Senturia 2001, 524)

The coalition members acknowledged widespread problems associated with community-based research, particularly research conducted in communities of color by predominantly white researchers (context). They demonstrated sensitivity (mechanism) to this history of mistreatment and, through mutual respect (mechanism), used their collective expertise to identify a locally relevant research agenda (outcome).

*Developing Program and Research Protocols.* In the Ramah Navajo Mammography Days partnership the community coalition members overcame barriers in planning the intervention by using their insider knowledge and preexisting resources:

System networking was initiated through the coordination of meetings between the coalition and the staff from the regional hospital where mammograms are performed and Ramah Navajo women are eligible for services (90 round-trip miles from the community). . . . One significant outcome of the first meeting was a willingness of the hospital staff to set aside 1 day every other month to accommodate 12 mammography appointments for Ramah Navajo women. . . . This networking also succeeded in encouraging members of the Women's Health program at the hospital to join the project coalition and attend future meetings to troubleshoot and brainstorm new ideas and strategies, thus broadening stakeholder participation and resource mobilization to increase community capacity. (\*English et al. 2006, 402)

Barriers to program implementation included distance from hospital resources to obtain mammograms (context). Coalition and hospital staff recognized their common health promotion goals and the merit of the project (mechanism). As a result, the hospital made accommodations to “bolster local infrastructure to increase access to mammography services” (English et al., 396) (outcome). In addition, membership of the coalition board expanded (outcome).

*Implementing Program and Research Protocol.* Community involvement also enabled culturally and logistically appropriate data collection. For example, in the East Side Village Health Worker Partnership, through their familiarity with and sensitivity to local issues, community members who were hired to conduct the block listing for the survey were able to overcome cultural and logistical barriers to survey implementation: “Community residents who participated in the block-listing process contributed invaluable knowledge of the community by locating hard-to-find units, accessing apartment buildings, explaining the presence of university participants to community members, and offering practical guidance on safety-related concerns” (\*Schulz et al. 1998, 17). According to one steering committee member, “The 81% response rate on the survey is a result of those efforts . . . which helped to increase community understanding of, and support for, the survey itself” (\*Schulz et al. 2001, 552).

The community's general mistrust of academic researchers (context) and socioeconomic challenges (context) led to the community's resistance or reluctance to getting involved in the research. Accordingly, the coalition members valued and used local knowledge (mechanism) to increase the residents' trust in the research process and overcome access barriers (outcome) and generate a high-quality survey (outcome).

*Interpreting and Disseminating Findings.* Partnership structures created opportunities for interpreting and disseminating research findings to enhance the mutual understanding of results and modify future research. The Kahnawake Schools Diabetes Prevention Project exemplifies how a community advisory board was able to translate scientific data into comprehensible research findings for dissemination to the wider community. The accessibility of the community's presentations led to further interpretations of the results by the community, which was incorporated into the research project:

Additional explanations for the increase in adiposity, which were suggested by residents in a series of local meetings to return research results to the community include increased overall community wealth and disposable income over the past decade combined with increasing availabilities of fast-food restaurants in the areas surrounding the reserve; increased proportion of families in which both parents work and are less available for supervision of children's meals and leisure activities; perceived importance, within the community, of computer literacy for youth. Longitudinal results for physical fitness are congruent with a reported decrease in physical education classes in 1 of the 2 schools in the intervention community during the period of 1994–1996. (\*Paradis et al. 2005, 337)

As a result of the long-term collaborative relationships between academic and community stakeholders (context), locally informed and accessible scientific study findings were presented to the community. The audiences at the presentations felt comfortable and safe participating in

the context of their community ownership of the project (mechanism) and made sense of the data in their own terms. As a result, new explanatory insights into the data were generated (outcome).

### *PR Generates Recruitment Capacity*

We found evidence of partnership synergy in generating recruitment capacity in three areas: (1) recruitment to steering committees and advisory boards, (2) recruitment for program implementation (i.e., lay health workers), and (3) recruitment as respondents to interventions and research projects.

*Recruitment of Community Members to Advisory Boards.* In *Messengers for Health*, recruitment to the advisory board was accelerated by the good reputation and connectedness of an initial community partner:

The initial partnership in *Messengers for Health* proved critical in gaining the trust of extended community partners because A.K.H.G.M. [an initial community partner . . . and a parent who lost a child to cancer] is a member of the tribe, is fluent in her language, and is a well-respected individual in the community. At an interview training session one year into funding, community women stated that they were interested in the project because this person was involved. (\*Christopher et al. 2008, 1402)

Although community members had reason to mistrust outside researchers (context), they felt *willing to participate* because they trusted (mechanism) the judgment of a well-respected and long-standing community member who was already involved. Trust, respect, and consequent synergy were established from this initial partnership, propelling subsequent stages of program planning (outcome).

*Recruitment of Community Members for Implementation of Program and Research Protocol (Specifically for Lay Health Worker Programs).* In *Messengers for Health*, Christopher and colleagues also demonstrated how PR facilitated the recruitment of participants

to implement programs. In this case, a nomination process by the community coalition members enhanced the recruitment of lay health workers (LHWs) from the community: “Community women, who were already known to be knowledgeable, sincere, compassionate and understanding were nominated as LHWs. This ensured the success of the program”

(\*Christopher et al. 2007, 3). Community coalition members knew the community well (context). The coalition *valued* (mechanism) this knowledge and preexisting relationships, and as a result, community members who were already known to have qualities that would make a good lay health worker were nominated (outcome). The participants’ trust and safety increased as a result of this careful selection process (outcome).

*2.3 Recruitment of, and Outreach to, Intervention Participants.* Recruitment also facilitated the enrollment of participants. This included the highly vulnerable population of the Complementary Medicine at the End of Life Project, which was a randomized controlled trial to investigate the role of meditation and massage in end-of-life care:

“The complex social, emotional, financial, and medical web that envelopes people at the end of life often forces nonessential commitments, such as participating in medical research, to be rejected. . . .

. . . Two senior Leeway nursing staff members, known to and trusted by the residents, were responsible for inviting residents to participate in the study and for obtaining informed consent.” [They] took the time to personally introduce the . . . staff to each participant at enrolment, tacitly endorsing their involvement with the residents. . . . The strategy resulted in 97% participation of eligible residents. (\*Williams et al. 2005, 92, 96)

Despite the difficult experiences at the end of life (context), residents at the facility *felt safe* (mechanism) participating, with the assurance of the endorsement from the nursing staff, which generated very high enrollment (outcome).

### *PR Develops Capacity and Competence of Stakeholders*

Partnership synergy resulted in the greater capacity and competence of both researchers and community stakeholders. Capacity and competence are related terms, in that capacity embraces the concept of readiness, whereas competence is how skillfully that capacity is applied to further community or individual goals (\*Goodman et al. 1998). Community stakeholders gained research knowledge and skills, which became assets for program planning and implementation. As a by-product, their collaborative experiences also led to more education and employment opportunities. Academic stakeholders gained capacity and competence from working with community partners to heighten their awareness of community issues and to cultivate the attitude, knowledge, and skills needed for partnering. Three outcomes resulted from the expansion of stakeholder capacity and competence: (1) benefits for the program through the growth of expertise, (2) benefits for other community projects and activities, and (3) benefits for personal and professional career development.

*Increased Capacity of the Community Partners.* In PoderesSalud/Power for Health, community health workers experienced a growth in professional skills associated with their participation in the project, leading to personal development and professional opportunities:

Community Health Workers (CHWs) mentioned their participation on the Steering Committee increased their knowledge of research. Additionally, the CHWs strengthened their professional skills, including computer skills, language skills, and meeting, planning and facilitation skills through their involvement with all aspects of the project. . . . The CHWs felt empowered by their role with the project, and a few of the CHWs sought additional training and similar CHW positions when the project funding ended. (\*Farquhar et al. 2008, 5)

The partnership offered formal and informal opportunities for training (context) that CHW recognized and valued (mechanism), which resulted in a sense of empowerment (outcome) and a search for additional training and employment positions (outcome).

*Increased Capacity of the Academic Partners.* In Project Bridge the academic partners acquired skills in collaborating: “Perhaps of greatest significance, faculty learned key skills in negotiating and collaborating with community-based organizations. This led to increased ability to appreciate and value the credibility of community stakeholders as authorities” (\*Marcus et al. 2009, 355). The partnership provided opportunities and experiences for academic partners to learn how to collaborate (context), which they valued (mechanism), resulting in their developing new and informed perspectives on community knowledge and leadership (outcome). In Witness for Wellness, the academic coalition demonstrated a willingness to relinquish control, became aware of their limitations, and learned how to collect community-based data:

The process [of collaborating] helped the academic partners understand the limitations of their expertise when designing evaluations for a community-based intervention . . . and community input allowed for creation of culturally appropriate and culturally meaningful evaluation. . . . The academic members of TW [Talking Wellness] learned to collect data effectively in community settings they would have never considered before the collaboration. (\*Chung et al. 2006, S1-75)

Again, the partnership provided the opportunity for increasing academic capacity and competence (context), which the researchers recognized and valued (mechanism), resulting in new awareness and skill in relating to community and enhancing data collection (outcome).

*PR Generates Disagreements between the Co-Governing Stakeholders during Decision-Making Processes, Resulting in Both*

*Positive Outcomes for Subsequent Program Planning.* The East Harlem Diabetes Center for Excellence demonstrated how the initial partnering process resulted in a radical shift in the direction of research. In the early stages of partnership formation, the academic coalition leader's idea for research was rejected outright by the community members. The partnership was able to proceed after coming to consensus on a completely different agenda:

The coalition's leader proposed a patient survey that focused on patient satisfaction with clinical encounters. This suggestion appeared to raise the level of mistrust in the coalition, because some members did not see the relevance of the proposed questions and were uncertain about how the data would be used. . . . In response to members' growing disinterest in, and dissatisfaction with the current coalition activities, and lack of group cohesion, coalition leaders asked members to articulate their vision for the Center of Excellence. Most members expressed their interest in shifting the focus of the coalition away from provider sites and toward the East Harlem community. (\*Horowitz, Williams and Bickell 2003, 543)

Stakeholders had no prior history together and lacked established trust in the group (context). Academic researchers were also unaware of community interests (context). By recognizing the value of agreeing on a research focus (mechanism), the researchers were able to create a change in direction and a new agenda to focus on health promotion/disease prevention efforts in the community (outcome). New trust was built among coalition members from the consensus-building process (outcome).

*Negative Outcomes.* In the Complementary Medicine at the End of Life Project, a randomized control trial was conducted under the guidance of a coalition comprising community residents, clinical staff, and academic researchers. Despite the high enrollment (owing to the presence of staff and residents on the steering committee), the control group was dissatisfied with the randomization, an issue that was never resolved:

Once the initial cohort had a favorable study experience, they provided informal endorsement via the “grapevine” among the community, further fueling the sense of injustice among those who were ineligible or in the control group. The researchers had particular difficulty translating the concept of randomization to the participants in the control group . . . several members of the control group felt cheated out of the intervention. . . . All of the collaborating partners met to discuss how best to address the inequity and betrayal felt among those excluded from the intervention. Various approaches . . . were considered, including providing a delayed intervention and/or subsidizing limited access to meditation and massage for all residents. After extensive deliberation . . . it became clear that addressing the residents’ perceived needs would involve a compromise of the randomized controlled methodology or a need for additional funding support. The former was not acceptable to the research partners, and the latter option was pursued unsuccessfully. . . . As a gesture of good will, and as an expression of gratitude from the academic researchers to the non participants, a desk top computer was provided to the common area at Leeway. (\*Williams et al. 2005, 99–100)

The palliative care setting was a highly sensitive environment (context). During the research-planning stage, the coalition decided to use experimental design methodology for the research (context). Despite signing consent forms, once the study began, the control group participants felt excluded (mechanism) from a potentially beneficial treatment that included massage and meditation. The issue was partially addressed through a gesture by the researchers in light of the residents’ negative feelings toward the partnership (outcome).

The Chicago HIV and Mental Health Project offers an example of harm to the recruitment process when the community coalition members were not consulted on key hiring decisions:

Without the direct input of community members, the university’s staff interviewed one individual for the role of community co-facilitator. . . . After the new facilitator missed several meetings . . . it was revealed that the facilitator had been arrested for drug involvement and was incarcerated. Community members had been aware of this individual’s problems with drugs. . . . This incident illustrated one of the potential benefits of community members’ involvement: knowledge of the community that can be used to enhance the integrity and quality of the research. It also illustrated the schism that exists between the principle and practice of a collaborative approach. Although the university was, in principle, committed to the idea of collaboration, in practice, it retained power and influence over certain key decisions. Likewise, although the community

assented to engagement in a collaborative research partnership, at the practical level, they were still mistrustful about the university's credibility and intent. (\*Baptiste et al. 2005, 380–81)

There was a lack of integrated collaboration at this point in the partnership, when the decision-making processes had not yet been defined (context). This led the research staff to feel it was appropriate to make a unilateral decision in a key hiring (mechanism). Their failure to use the insiders' knowledge resulted in an inappropriate hiring decision and consequent disruption to the program (outcome).

*PR Synergy Builds Momentum through Repeated Successful Outcomes in Partnering, an Increase in the Quality of Outputs, and Outcomes over Time*

Our realist analysis provided evidence that synergy has the potential to build over time when the partnership's activities repeatedly produce successful outcomes. This evidence was synthesized by identifying the outcome of one CMO configuration as forming part of the context in the next phase of research along a chain of planning and implementation stages—what we call a “C<sup>1</sup>M<sup>1</sup>O<sup>1</sup>-C<sup>2</sup>” pattern, in which outcome<sup>1</sup> becomes a contributor to context<sup>2</sup>. This demonstrates how partnerships alter elements of context overtime, leading to enhanced outputs and outcomes. For example, in the East Baltimore Asthma Prevention Program (\*Swartz et al. 2004), the careful design of participatory processes from the outset led to greater synergy and incrementally positive outcomes for a community-based clinical trial, which can be seen in the following quotations:

There were concerns [by academic stakeholders] that conducting a complex clinical trial requiring structured outcome collection and adherence to study regimens in a community of families that frequently moved and changed telephone numbers might not be possible. (p. 164)

With the encouragement of the CAB [community advisory board] to promote acceptance and the establishment of an open, honest two-way relationship between participants and the study, the entire community staff was [chosen to be] African-American and either lived or had lived in the community or had previous work experience in research or education in the community. (p. 158)

They [community staff] attended community meetings, participated in community health fairs, and helped families with social problems outside the scope of the study. Their roles in the study extended beyond their research duties and into the community. This provided them with a larger purpose, making them more enthusiastic and invested in the study. Also, because they were so intensely involved in the community, their research jobs were easier. (p. 164)

Ultimately we believe it was the strength of the personal relationships with the study staff that kept participants engaged in the study. (p. 165)

Through close interaction with the community, staff members sometimes were made aware of families interested in participating but whose children had not been through the school-based asthma education program. As a result, an alternate method of recruitment was developed. (p. 159)

We were pleased that we were able to enroll a high percentage of eligible families and, despite a high rate of changes in living arrangements, had such a high retention rate. We believe this was due primarily to the trust created by the overall project and the people working for the project. As the study unfolded, we learned a great deal about ways to keep families engaged. When we encountered follow-up problems, possible courses of action were discussed with field staff and strategies developed. (p. 164)

Barriers to conducting a randomized community trial included community resistance and the demands placed on them given the complex and structured research protocol (context<sup>1</sup>). A decision was made at the outset to hire only African-Americans familiar with the community as project staff (context<sup>1</sup>). Because of their prior history in the community, the project staff were glad to assist community members beyond the scope of the study (mechanism<sup>1</sup>). This led to the staff's greater investment in the project (outcome<sup>1</sup> → context<sup>2</sup>). The staff's deepening investment increased the community members' trust in the project (mechanism<sup>2</sup>), resulting in closer interactions between the project staff and the community members (outcome<sup>2</sup> → context<sup>3</sup>).

Because of the greater sense of trust and safety (mechanism<sup>3</sup>) due to the previously described trust-building processes, some participants revealed their desire to enroll in the project even though their children had not participated in the school-based asthma program (outcome<sup>3</sup>). This led to new methods of recruitment being developed (outcome<sup>3</sup> → context<sup>4</sup>), and new recruitment methods led to higher than expected enrollment (context<sup>4</sup>). This added to the project stakeholders' desire to overcome attrition obstacles (mechanism<sup>4</sup>). As a result, a new capacity to retain participants and prevent attrition in a complex clinical trial was created in a mobile population by addressing problems as they arose and through the project stakeholders' increasing sense of motivation, trust, and co-ownership of the project (outcome<sup>4</sup>).

*Partnership Synergy Accumulates Capacity to Sustain Project Goals beyond Funded Time Frames and during Gaps in External Funding*

Funding gaps in community-based programs are common. We encountered examples in which partnership synergy had made it possible to sustain programs despite such gaps. For example, in the WORD Faith-Based Weight-Loss Program, lay health workers and church groups involved in the project strengthened their ties to enhance their work on obesity prevention efforts even after the intervention had been completed:

The use of the lay health advisor model enhanced the possibility of program sustainability through building on natural social networks within the faith community in an economical way. From the program, pre-existing networks were strengthened and new ties were formed. In-depth interviews with WORD Leadership team members revealed evidence of greater community cohesiveness, particularly between churches that had not interacted with each other in a considerable way before. (\*Hye-cheon et al. 2006, 647)

The involvement of trained lay health workers and church groups who implemented the weight-loss intervention gained leadership and expertise on weight-loss issues affecting their

community (context). They felt inspired (mechanism) to continue working for this cause after the project ended, resulting in strengthened ties with one another and other church organizations (outcome).

Synergy generated from successful outcomes early in partnership activities also made it possible to sustain programs despite gaps in external funding. For example, in the Kahnawake Schools Diabetes Prevention Project (KSDPP), community buy-in after initial project successes generated critical bridge funding:

KSDPP was implemented in an era of scarce research funding and needed to find new funding sources after the first three-year research grant ended. Due to early success of the project and high level of community support, three community organizations chose to continue funding for one year. . . . The following two years . . . were funded by private foundations combined with community contributions. This critical period of bridge funding allowed KSDPP to continue, and two years later the team was well positioned to apply for innovative national research grant monies designated for university-community partnerships, which led to five years of infrastructure funding. (\*Macaulay et al. 2006, 13)

Despite the scarcity of funding sources (context) and because of the project's early success (context), as well as widespread concern about the implications of diabetes for children in the community (context), the community members wanted to find community-based sources of bridge funding (mechanism), which enabled the partnership to apply and receive five years of infrastructure funding (outcome).

### *PR Generates Systemic Changes and New Unanticipated Projects and Activity*

Partnerships were capable of effecting systemic changes beyond their immediate project goals because of their integration into local contexts. Policy advocates and influential community

leaders who also were coalition members were often credited for such effects. Numerous systemic changes were noted in the Vietnamese Reach for Health Initiative:

Partly due to the coalition, the State of California re-established the Breast and Cervical Cancer Control Program [which had been previously shut down] in 2003. . . . The Coalition worked closely with state officials to ensure cultural appropriateness of services and to publicize the program. Other examples of system change included the creation of the Vietnamese Pap clinic, increases in physician knowledge and offering of Pap tests, and creation of the reminder system. (\*Nguyen et al. 2006, 43)

From the success of the project (context), coalition members were motivated to advocate system changes for cancer prevention in the Vietnamese community (mechanism), which had a lasting effect beyond immediate intervention (outcome).

We further observed that with the increased capacity and competence of co-governing stakeholders, new unanticipated projects and activities were created. In some cases, members contributed their acquired skills to other projects. For example, in Project TEAL: Tribal Efforts Against Lead, their partnership activities inspired some members to work on related projects addressing lead poisoning:

An NIEHS-funded Children's Environmental Health Center now works with TEAL members and former staff on several associated research projects. . . . The TEAL project's impact, moreover, continues to be felt in other ways. For example, in 2006, TEAL partners began to plan a book and a documentary film telling the story of TEAL and other key players in addressing lead poisoning and environmental devastation in the Tar Creek region. (\*Petersen et al. 2006, 253)

Project TEAL was very successful in acquiring high-quality, credible scientific data (context). The coalition members wanted to capitalize on this success (mechanism) to work with other groups on lead poisoning prevention (outcome) and to plan a book and documentary on their experiences (outcome).

The Cambodian Community Health Program 2010 demonstrated how an unanticipated outcome, an influential self-initiated Cambodian Elders' Council, had positive implications beyond the partnership's immediate goals:

The Elders council evolved at the suggestion of several elder program participants; it functions as an advisory group to the program and as a bridge and leader in the community. An additional role has been to enhance the cultural understanding of Cambodian health and human service staff, particularly those who left Cambodia. . . . [Elder speaking]: This gesture [forming the coalition] looks meaningless to those who live in a democratic state, but if for years, emotions are forbidden to be shown, this is one giant step for Cambodian elder women. (\*Grigg-Saito et al. 2008, 421)

In the context of an open and responsive partnership that encouraged community members to contribute to the program's design (context), elders in the community felt safe and supported (mechanism) in forming an elders' council (outcome), which led to better cultural education of service staff (outcome), and self-empowerment of the elders (outcome).

## **Discussion**

Our findings provide compelling evidence that multistakeholder co-governance can be beneficial to research contexts, processes, and outcomes in both intended and unintended ways and can occasionally contribute to negative outcomes. To access such evidence, we expanded the scope of assessment beyond a narrowed synthesis of intervention outcomes from peer-reviewed journal articles to include any and all outcomes seen as arising from participatory processes in the published and gray literature. In a realist review, building a coherent and plausible explanation of the data through middle-range theory is as important as gathering evidence. Without such conceptualizing, our assessment would not have had a focus; we would have missed many configurations; and our conclusions would have been truncated. Partnership synergy theory was

critical to helping shape the synthesis. Through the synthesis process using CMO configuring, we refined the theory by demonstrating that synergy is both an outcome and a context for partnership development—so that when synergy generated positive outcomes (e.g., enhanced trust or improved data collection), those outcomes generated new synergy. Expanding this logic, we demonstrated how partnership synergy created momentum over time, producing resilience in the face of obstacles as well as sustaining health-related goals, extending programs and infrastructure, and creating new and unexpected ideas and activities. The success of applying and refining this theory had to do with its having explanatory power across a broad range of PR practices. Regardless of the more specific drivers of such practices, such as knowledge utilization, self-determination, and social/environmental justice (\*Cargo and Mercer 2008), partnership synergy appeared to be a universal feature of collaborative processes for those partnerships meeting our inclusion criteria.

In addressing the issue raised by authors of a number of previous reviews concerning the difficulty in measuring the extent of PR's impact on health disparity (\*Berkowitz 2001; \*Kreuter, Lezin, and Young 2000; \*Viswanathan et al. 2004), our synthesis revealed that such disparity was reduced by the effects of enhancing programs themselves, as well as by so-called intermediate outcomes of participation. These latter outcomes, such as capacity building, self-empowerment, and infrastructure development, were sometimes described as having a more profound impact on well-being than did the intended outcomes of planned interventions. While a given intervention (e.g., for cancer prevention) increased the number of positive health changes (e.g., an increase in the number of diagnostic tests completed in an underserved community), the capacity and self-empowerment gained while partnering had an immeasurable long-term impact,

altering the destiny of communities through acquired skills, self-determination, and empowerment.

In addressing the findings of the one previous systematic review of PR in health commissioned by the Agency for Healthcare Research and Quality (\*Viswanathan et al. 2004), our findings confirmed what had been previously noted regarding improved research quality and capacity building in PR. We extended the assessment, however, to uncover new benefits for the outcome of productive conflict and negotiation; long-term synergy building (the positive outcome of one stage leads to a better context for the next); the ability to mitigate funding gaps, invoke sustainability, and extend programs; and create new unanticipated projects and activity. The evidence concerning conflict, disagreement, and negotiation in creating positive outcomes requires an explanation. The coalitions experienced stages of program and research planning in which stakeholders disagreed on, for example, the research agenda and/or aspects of intervention design and implementation. In such cases, disagreement was not necessarily antithetical to the group's synergy; on the contrary, it often increased synergy through successful negotiation and resolution. Disagreement was often an opportunity for the researchers to show their good intentions to work with the community—to listen, negotiate, modify their thinking and approach, and arrive at consensus—and in some cases allowed community members to learn about and gain appreciation for rigorous scientific methods. It also permitted approaches unlikely to work to be identified and abandoned at early stages. Such positive outcomes established trust and respect where they previously were not well established and deepened the stakeholders' commitment to the project. Successful outcomes of conflict resolution in partnerships became a part of the partnership context for subsequent phases of research. Synergy, built on a series of successes, increased the chances for future success. We concluded that healthy conflict,

resistance, negotiation, and consensus building are integral to establishing trust and rapport among stakeholders. Alternatively, unresolved conflicts, while rare in the documented data, led to disaffection and a breakdown in the trusting relationship between stakeholders.

### *Limitations and Directions for Future Research*

A possible publication bias in primary studies toward reporting only the successful outcomes of partnerships is a potential limitation of this review. Thus although we sought, but did not find, disconfirming cases to challenge our demi-regularity statements, we are now interviewing PR stakeholders, because we hypothesize that such cases will likely be revealed only through qualitative interviews. In addition, although the realist approach can create a more encapsulating view of the evidence, the literature has not been written to be read with such a viewpoint.

Therefore our theory-based approach leaves many questions unanswered, for which new research and, equally important, new reporting styles are needed. Such reporting styles need to describe more accurately the breadth and scope of PR impacts on research and health outcomes. In looking for the evidence corresponding to our threefold division of preexisting, generating, and accumulating factors, the area that is best reported in the literature pertains to the generating factors of PR. This is because the literature is marked by stakeholders themselves reporting what was generated from their collaborations. In contrast, better understanding the role of preexisting and accumulating factors for PR assessment requires further research. This may include realist evaluations of primary PR studies as well as qualitative interviews with both academic and community stakeholders to gain perspectives from their direct experience, and also prospective studies of new PR partnerships.

Because we had limited resources and were working with a large body of literature, we included in this review only community-based PR and not other forms, such as PR with institutions, health services, and policymakers. These diverse PR practices could be explored in a further review. Additionally, although the recruitment advantage in PR was shown to benefit all stakeholders, a critical view may reveal that some funding or research institutions' reason for pursuing PR is to increase enrollment in clinical trials, reduce refusals, boost sample sizes for surveys; to acquire community support for random assignment to control groups; or to increase knowledge translation activities only (\*Trickett 2011). While these issues require serious attention, our results are applicable solely to "full participation" PR, which emphasizes equity and co-governance with community stakeholders who have formal power to challenge and change the research agenda. We also fully acknowledge that high-quality research with beneficial outcomes has emerged from collaborative research that did not meet these criteria for "full partnership" (e.g., \*Coady et al. 2008; \*Hinton et al. 2005), but our theoretical explanations in this article do not necessarily pertain to such studies.

### **Conclusion: Implications for Health Research and Practice**

As interest grows in collaborative partnerships in health-related research, new measurement tools and methodologies are needed to inform our understanding and evaluation of these collaborations. In this article, our contribution has been to pioneer and tailor a relatively new methodology, a realist review, for the assessment of the PR literature. As a result, we have confirmed previous systematic review findings and numerous case studies (i.e., increased recruitment and response rates, capacity building) and also uncovered a multitude of potential benefits (including positive outcomes from conflict and unanticipated outcomes) that were not

found or explicitly highlighted in previous reviews. We conclude that participatory research is a favorable approach to research, supporting health by improving research quality, empowerment, capacity building, sustainability, program extension, and unanticipated new activities. The implications of such findings are relevant to a broad spectrum of health research and practice. We hope that the findings presented here will support the design of new partnerships and PR assessments; inform policies for ethical review, peer review, and editorial assessment; and provide insight into the benefits of PR for health intervention research.

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## **Appendix**

### **Additional Information on Retained Partnerships**

Abbreviated Title	Health-Related Goals	Methods	Number of CMO Configurations	Duration
1. Cambodian Community Health 2010	Cardiovascular disease and diabetes prevention	QUAL & QUAN (obs.)	2	12+ years
2. The WORD (Wholeness, Oneness, Righteousness, Deliverance)	Weight loss	Mixed methods	5	8-week intervention
3. Kahnawake Schools Diabetes Prevention Project	Diabetes prevention	QUAL & QUAN (obs. & exp.)	11	17+ years
4. Improving mammography screening for American Indian women in New Mexico	Breast cancer prevention	Mixed methods	7	6 years
5. East Harlem Diabetes Center of Excellence	Diabetes prevention	QUAN (Obs.)	7	11 years
6. 'Imi Hale—Native Hawaiian	Cancer prevention	QUAL	16	11+ years

Cancer Awareness, Research, and Training Network		&QUAN (obs. & exp)		
7. Collaborative HIV Prevention and Adolescent Mental Health Project (CHAMP)	HIV prevention	QUAN (obs. & exp)	12	13 years
8. Vietnamese Reach for Health Initiative	Cervical cancer prevention	QUAN (obs. & exp)	11	25+ years
9. QueensCare Health and Faith Partnership	Childhood trauma reduction and prevention	QUAN (obs. & exp)	11	17+ years
10. Witness for Wellness	Depression awareness and prevention	QUAL & QUAN (obs.)	12	7 years
11. Targeting cancer in blacks	Cancer prevention	QUAL & QUAN (obs. & exp)	2	3 years
12. Project BRIDGE	Substance abuse prevention	QUAN (obs.)	10	7 years
13. Asthma education program in East Baltimore	Childhood asthma prevention	QUAL & QUAN (obs.)	10	1 year
14. East Side Village Health	Health promotion	QUAN (obs.)	19	10 years

Worker Partnership

15. Nuclear Risk Management for Native Communities (NRMNC)	Nuclear risk management	QUAL	15	7 years
16. Poder es Salud / Power for Health	Health promotion	QUAL & QUAN (exp.) & mixed	3	3 years
17. Study of Complementary Medicine Interventions at End of Life	Palliative care using massage and meditation	QUAN (exp.)	4	1 year
18. Internet access for health-related empowerment	Health promotion	QUAN (exp.)	2	2 years
19. Seattle Partners for Healthy Communities	Health promotion	QUAL & QUAN (exp.)	15	7 years
20. The Haida Gwaii Diabetes Project	Diabetes prevention	QUAL & QUAN (obs.)	4	5 years
21. Messengers for Health	Cervical cancer prevention	QUAL & QUAN (obs.) & mixed	7	10 years
22. Asthma Research in an inner-	Asthma prevention	QUAL &	4	3 years

city Latino neighborhood		QUAN (obs. & exp.)		
23. Tribal Efforts Against Lead (TEAL)	Lead poisoning awareness and prevention	QUAL & QUAN (obs. & exp.)	8	10 years

*Legend:* QUAL: Qualitative Research, QUAN: Quantitative Research, Obs: Observational Study, Exp.: Experimental Study.