

# The Value and Challenges of Participatory Research: Strengthening Its Practice<sup>\*†</sup>

Margaret Cargo<sup>1,2</sup> and Shawna L. Mercer<sup>3</sup>

<sup>1</sup>Department of Psychiatry and Douglas Mental Health University Institute, McGill University, Verdun, Quebec H4H 1R3, Canada

<sup>2</sup>Current address: School of Health Sciences, University of South Australia, City East Campus, Adelaide, South Australia 5001; email: margaret.cargo@unisa.edu.au

<sup>3</sup>The Guide to Community Preventive Services, Division of Health Communications, National Center for Health Marketing, Centers for Disease Control and Prevention, Atlanta, Georgia 30333; email: smercer@cdc.gov

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## Key Words

Community-based participatory research, action research, empowerment evaluation, community engagement, partnerships, knowledge translation

## Abstract

The increasing use of participatory research (PR) approaches to address pressing public health issues reflects PR's potential for bridging gaps between research and practice, addressing social and environmental justice and enabling people to gain control over determinants of their health. Our critical review of the PR literature culminates in the development of an integrative practice framework that features five essential domains and provides a structured process for developing and maintaining PR partnerships, designing and implementing PR efforts, and evaluating the intermediate and long-term outcomes of descriptive, etiological, and intervention PR studies. We review the empirical and nonempirical literature in the context of this practice framework to distill the key challenges and added value of PR. Advances to the practice of PR over the next decade will require establishing the effectiveness of PR in achieving health outcomes and linking PR practices, processes, and core elements to health outcomes.

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**CBPR:**

community-based participatory research

**PR:** participatory research

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## INTRODUCTION

Interest in participatory research approaches in public health has been increasing over the past decade because of their potential to improve health and eliminate health disparities by bridging gaps between research and practice, addressing social justice, and creating conditions that facilitate people's control over the determinants of their health (49, 118). This potential has been compelling for many reasons. Although *Healthy People 2010* has identified the elimination of health disparities as one of its two overarching goals (126), recent reports note that little progress has been made (1, 23, 127). Decision-makers, advocates of underserved populations, researchers, and intended users have questioned the social and cultural validity of studies conducted by researchers who know little about the people, culture, and setting in which their research was done (21, 31, 32, 115, 135), and whether research findings from one setting can be applied to other situations, contexts, and populations (35, 43, 82). Moreover, many communities express dissatisfaction when external researchers parachute in, conduct research on community members, and leave without providing information or assistance (43, 78, 135). A parallel frustration has arisen among practitioners and policymakers regarding research that does not address their specific needs or resource limitations (113, 142). In addition, transforming the conditions that influence health requires broad-based collaborative partnerships between academic and nonacademic stakeholders and beneficiaries (9, 24, 103, 126). Finally, experience has shown that when intended users, stakeholders, and other research beneficiaries are engaged up front in the research planning process, they are more committed to using the research findings to take action (65, 71).

Some of these considerations led the Institute of Medicine (IOM), in its influential *The Future of the Public's Health in the 21st Century*, to underscore the importance of authentic community engagement in the pub-

lic health system and highlight the promise of community-based participatory research (CBPR) (48). Furthermore, the equally influential IOM report *Who Will Keep the Public Healthy?* designates CBPR as a new content area for public health and recommends its inclusion in graduate-level public health education (49).

We were charged with the task of conducting a critical review of the empirical and nonempirical literature from the past decade to identify the value and challenges of PR approaches. The review is based on the critical appraisal of more than 300 peer-reviewed publications, books, government reports, and other documents identified from electronic journal databases (i.e., Medline, Psychlit), the gray literature, and federal, organizational and agency-level Web sites. This review begins by defining PR in public health. We then present an integrative practice framework that emerged from our efforts to consolidate the growing and heterogeneous applications of PR approaches in public health, and we discuss each domain of the framework and its related challenges. Next, we summarize the state of the field and conclude with recommendations for more fully institutionalizing and sustaining PR in public health.

## DEFINING PARTICIPATORY RESEARCH IN PUBLIC HEALTH

We use participatory research (PR) as an umbrella term for a school of approaches that share a core philosophy of inclusivity and of recognizing the value of engaging in the research process (rather than including only as subjects of the research) those who are intended to be the beneficiaries, users, and stakeholders of the research (41, 43, 51, 133). Among the approaches included within this rubric are CBPR (52, 88), participatory rural appraisal (13), empowerment evaluation (29, 30), PR (41), participatory action research (61), community-partnered PR (59), cooperative inquiry (46), dialectical inquiry

(111), appreciative inquiry (19), decolonizing methodologies (120), participatory or democratic evaluation (44), social reconnaissance (114), emancipatory research (25), and forms of action research embracing a participatory philosophy (7, 124). CBPR is currently one of the more widely recognized PR approaches, with a growing number of applications, particularly in geographic and racial/ethnic communities (130). The benefit of considering all PR approaches collectively, however, is underscored by the valuable work undertaken using other PR approaches and the fact that, despite attempts to broaden the definition of “community” beyond geographical or geopolitical units to include those sharing common characteristics or interests (43), many working in policy- and practice-based public health do not see some of the tenets of research with communities as applicable to their particular circumstances (35, 37, 59, 103).

PR is broadly 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” (41). PR is unique among public health research approaches in combining research with education (or colearning) and coordinated collaborative action to democratize the knowledge production process (30, 41, 57, 124). Community members, practitioners, health professionals, and organizational and institutional representatives directly affected by or implicated in a given health issue are not situated on the periphery of the knowledge production process; instead, they partner with academics to produce knowledge with the potential to offer practical solutions. A key strength of PR is the integration of researchers’ theoretical and methodological expertise with nonacademic participants’ real-world knowledge and experiences into a mutually reinforcing partnership. Furthermore, aggregation of diverse partners’ financial, in-kind, social, and material resources enables more comprehensive and coordinated responses to public health issues than any single stakeholder could achieve (69, 89, 140).

PR is becoming defined, in part, by the heterogeneity of its applications. Historically, PR was influenced by the utilization-focused action research tradition of Kurt Lewin (known as the “Northern tradition”) and the emancipatory PR tradition inspired by Paulo Friere (“Southern tradition”) (133). Once distinct forms of inquiry with little evidence of cross-fertilization (8), the evolution of these two forms of inquiry has led to a blurring of boundaries and the formation of hybridized participatory approaches within public health (133), including, for example, integration of CBPR principles into practice-based research networks (59, 76) and mental health services research (141). A third root of PR is the growing self-determination and sovereignty movement of American Indians (15, 78), indigenous Australians (112), the Maori people of New Zealand (45), and Canada’s First Nations, Métis and Inuit peoples (12, 22). These three roots are united by the drive to create scientific knowledge with those who are most affected by the issue being studied and, through the application of that knowledge, to make a difference in public health practice and action.

Because PR is an approach (41), orientation (89) or way of working (121), it can employ a diverse range of study designs, methodologies, and methods (52, 88)—from environmental assessments (74, 80, 119) to randomized controlled trials (62), photovoice (137), and qualitative case studies (53, 87). The scientific merits of PR have traditionally been judged according to the standards of researchers’ disciplinary and/or methodological areas of expertise: internal and external validity for quantitative research and credibility and transferability for qualitative research. The recent emphasis on knowledge translation further underscores the importance of considering social validity (32) and cultural validity (91) as additional standards for assessing research relevance and community engagement.

Clear sets of PR principles (30, 57, 59), guidelines (41) and steps (124) have been

developed to guide partners in designing, implementing, and evaluating PR initiatives. Israel and her colleagues (56), for example, first presented their principles for CBPR a decade ago; the most recent version appears in their article on CBPR methods (51). In 1995, Green and his colleagues (41) developed a set of 25 guidelines for PR to assist academic researchers and their partners in designing PR and funders and evaluators in assessing PR. One of the current authors (Mercer) recently led extensive reliability testing of the guidelines; the revised version is forthcoming. The ten principles of empowerment evaluation (29), implicit in a 1996 document, have been made explicit in the newest edition of the text (30). Although not an exhaustive list, these principles, steps, and guidelines—which have evolved in response to their application in the field—provide academic and nonacademic partners with a refined set of tools to help bridge the overall approach of PR with its practice.

## AN INTEGRATIVE PRACTICE FRAMEWORK TO GUIDE THE DESIGN, IMPLEMENTATION, AND EVALUATION OF PARTICIPATORY RESEARCH

Many academic researchers and their partners struggle with how to operationalize PR principles, steps, and guidelines across the lifespan of their PR efforts. In reviewing the diverse and growing PR literature to identify the value and challenges associated with putting these principles, steps, and guidelines into practice, we experienced difficulty disentangling which partners were involved in what phases of the research, when, and for what purposes. From our critical review of the literature, we distilled an integrative practice framework that provides academic and nonacademic partners with a structured process for developing and maintaining their partnerships as they design, implement, and evaluate their PR efforts and account for intermediate and long-term outcomes. This integrative practice framework

includes five domains, which are shown in **Figure 1** and identified here in the form of the question each domain must address:

1. What are the values or drivers behind the research?
2. Who should participate in the research, and how should they participate?
3. How are partnerships initiated, and how do they evolve?
4. What are the core elements of PR?
5. What is the added value of PR in each of the research phases?

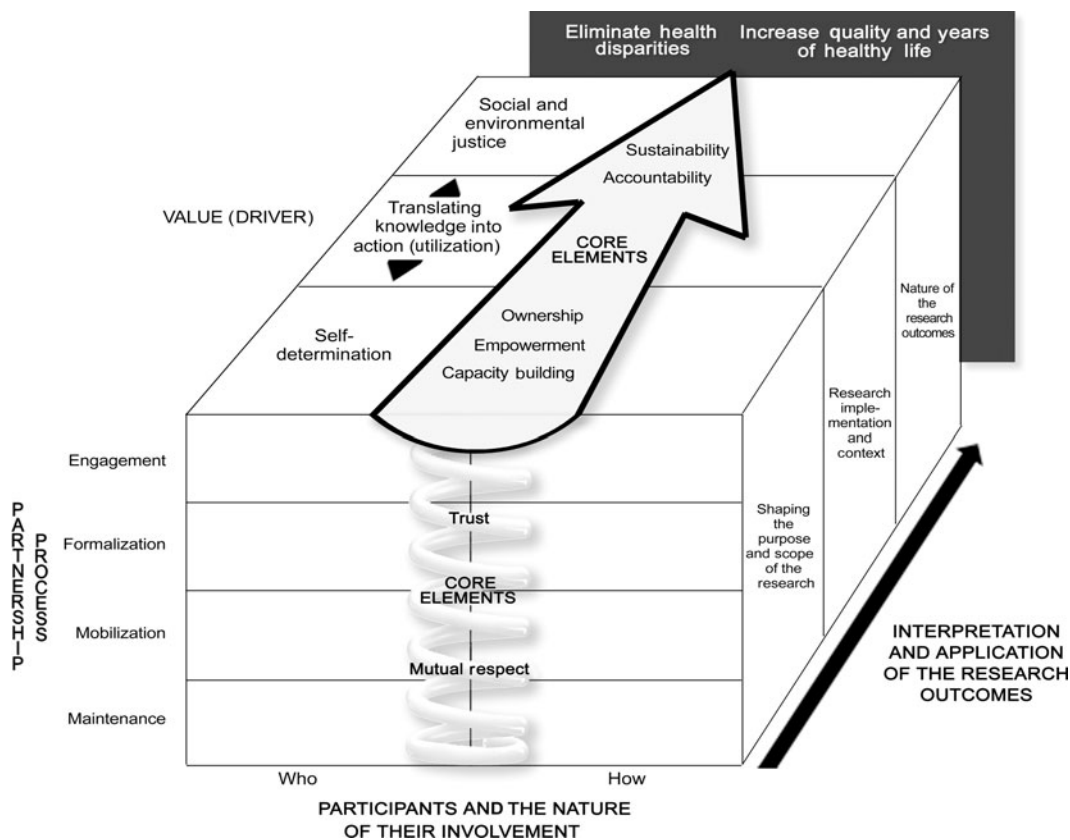
Addressing these questions can guide the application of PR principles, guidelines, and/or steps to the range of public health issues for which PR is suited. This framework can be used with descriptive, etiological, and intervention studies as well as evaluations of programs or policies. Domains and their interrelationships are discussed below.

## WHAT ARE THE VALUES OR DRIVERS BEHIND THE RESEARCH?

Although all PR approaches in public health seek to create knowledge by bridging knowledge-to-action (KTA) gaps (37), our critical review of published studies suggests that the primary values or driver(s) for the research can be distinguished by the emphasis placed on knowledge translation relative to social and environmental justice and self-determination. Identifying the driver(s) of the research is essential for academic partners to adopt the most appropriate strategies for engaging nonacademic partners in ways that respect and fit with their contexts and realities. We distinguish the drivers in **Table 1** and review them below.

## Translating Knowledge into Action (Utilization)

Knowledge translation, or translating research into practice—also described as knowledge or research utilization, dissemination,



**Figure 1**

An integrative practice framework for participatory research.

transfer, implementation, and exchange—has emerged as a key integrating concept to address the “know-do” gap in public health (35, 64). Policy and practice decision makers—administrators, program coordinators, and frontline workers—grapple with how to improve the development, implementation, and delivery of programs and services. PR driven by knowledge translation builds on the utilization-focused “Northern tradition” (8, 133) in seeking to produce knowledge that addresses the real-world needs of these policy and practice decision makers and facilitate its translation into action in the form of practice, policy, or behavior change in individuals, organizations, or systems. PR applications driven by knowledge translation include engaging with decision makers to inform health

service priority setting (6, 99) and with practitioners and administrators to strengthen capacities of health units delivering heart health promotion programs (58). Partnerships typically include decision makers and academic investigators in the research process, with or without end users. Projects with an intermediate goal of empowerment, and that engage end users and their support networks in addition to service providers and administrators, are more strongly aligned with PR ideals (58, 124, 143).

### Social and Environmental Justice

PR driven by values of social or environmental justice gives primacy to the needs and interests of those situated at the bottom of vulnerability

**Table 1 Distinguishing values or drivers in participatory research approaches in public health**

|                       | Value (driver)   |   |   |
|-----------------------|--|---|---|
|                       | Translating knowledge into action  | Social and environmental justice  | Self-determination  |
| Tradition             | Utilization focus  | Popular education   | Rights perspective  |
| Intent                | Primarily for research to improve the delivery and management of public health programs, services, and other products that impact health disparities and health status | Primarily for research to ameliorate social and environmental disparities by promoting capacity building, empowerment, and ownership (“emancipation”) to improve population health status | Primarily for research to reflect people’s right to self-determination in relation to their health by promoting ownership, control, access, and possession of the collection and application of health information for collective benefit |
| Common applications   | <ul style="list-style-type: none"> <li>• Organizational development</li> <li>• Public health system development</li> <li>• Practice-based research networks</li> </ul> | <ul style="list-style-type: none"> <li>• Community development</li> <li>• Practice-based research networks</li> </ul>   | <ul style="list-style-type: none"> <li>• Community development</li> <li>• Community economic development</li> </ul>   |
| Typical PR approaches | Empowerment evaluation, utilization-focused evaluation, participatory action research, participatory research, appreciative inquiry                                    | CBPR, community-partnered participatory research, empowerment evaluation, participatory research  | CBPR, decolonizing methodologies, participatory research, empowerment evaluation  |

hierarchies. These include the “victims” of social and environmental injustice themselves as well as community organizers, public health workers, and policy makers, for example, who struggle to bring scientific evidence to bear on the problems confronting their communities because of insufficient power and resources. Drawing on the rich history of the Southern emancipatory tradition (8, 133), approaches such as CBPR (56, 88, 89) and empowerment evaluation (29, 30) address the *Healthy People 2010* goal of reducing health disparities based on race, ethnicity, and social class (48, 135). Partnerships creating conditions conducive to consciousness raising and mutual learning are critical for galvanizing communities to act and attain emancipation. Community participation in the research process enables individual, interpersonal, organizational, and community empowerment, ownership, and capacity building (130, 132). Because partnerships are formed with marginalized, underserved, and vulnerable populations, the con-

cepts of cultural humility and cultural safety are integrated into processes for academic and nonacademic partners to establish and maintain mutual respect and trust (51, 84, 135). Partnerships ultimately seek to change the root causes or material circumstances that produce and reproduce health inequalities in society (96). CBPR has been applied to reduce health disparities in a broad array of initiatives (80, 93, 116, 128, 129, 136).

### Self-Determination

Some PR applications are driven by the value of self-determination: broadly defined as the capacity of individuals and groups to chart their own courses. This approach has emerged parallel to the sovereignty movements of indigenous peoples (2, 106) and the desire for other marginalized and underserved populations (e.g., HIV/AIDS and disability movements) to assert control over the research and programs that affect them. These groups

approach research from a rights perspective. For many indigenous people and other groups, these rights are operationalized in written codes of research ethics and memoranda of understanding, which outline their access, control, ownership, and possession of the data and use of information (78, 106, 115). Particularly prominent with this driver is the high degree of nonacademic partners' ownership and regulation of the research process from the outset and academic partners' recognition of the rights of the population to make decisions about issues that affect its collective health (12, 21). Community-directed or controlled research ensures that the partnership utilizes and builds on local strengths and resources in conducting the research.

## WHO SHOULD PARTICIPATE IN THE RESEARCH AND HOW SHOULD THEY PARTICIPATE?

### Who Should Participate?

Identifying who should participate in a partnership has emerged as a critical issue (43, 67) for many reasons. First, researchers agree that the risk factors and conditions affecting public health require systems-level and ecological solutions that go beyond the expertise, resources, or control of any one program, organization, or sector (5, 42, 48, 67, 110, 123). This ecological complexity favors transdisciplinary engagement of academic partners to integrate and extend knowledge in new ways and the inclusion of sectors such as housing, economics, industry, and faith-based organizations (5, 9, 123). Second, the diversity of issues, populations, and settings to which PR has been applied has led academic researchers to engage with different types of communities that may exist or emerge through defining the research purpose (50). Communities of interest—whether geographically bound or not—are typically defined by individuals collaborating around a shared interest, need, issue, or problem (43, 76, 123, 141). Third, although partnerships tend to engage repre-

sentatives from a wide range of constituencies, the absence of common terminology hinders identification of who should be involved to maximize collaborative advantage in relation to the study purpose and values (69) (see **Figure 1**). To address this issue, we offer terminology derived from an ecological approach (108) to distinguish types of partners on the basis of their expertise, access to resources, influence, interest, and ability to represent intended users, beneficiaries, and stakeholders of the research. A first level of distinction is made between academic and nonacademic partners.

Academic partners are affiliated with an academic or research institution and involved in some combination of research, service, and teaching (academic researcher) or in an administrative capacity (academic administrator). It is important to recognize the discipline (e.g., epidemiology, social work) and type of expertise (e.g., research, service) contributed by academic partners. Cross-disciplinary research, service, and administration perspectives may be needed to (*a*) inform the theories that guide the research; (*b*) guide the methodological approach to data collection, analysis, and interpretation; (*c*) harness problem-solving, facilitation, and organizing skills to mobilize a community of interest; and (*d*) bridge knowledge-to-action gaps (103, 138, 144). Because academic researchers rarely have all the necessary skills for a given PR effort, they need to partner with others who have complementary expertise (122).

Five types of nonacademic partners exist: (*a*) clients, consumers, or other ultimate beneficiaries of the PR effort—the group in which change can be measured (end users); (*b*) the interpersonal support network of the end users—including family members, mentors, friends, etc.; (*c*) the general public, who are not end users but support or believe in the issue; (*d*) those who interface directly with end users and/or end users' interpersonal networks, including practitioners, health professionals, teachers, administrators, and other pertinent staff (service providers); and

**Table 2** Questions to guide the identification of the optimal mix of partners in participatory partnerships

|    |  |
|----|--|
| 1. | Who are the end users and beneficiaries of the research products, and what is the added value of their participation in the partnership?   |
| 2. | Which academic disciplines should be represented in the partnership to address the ecological complexity of the determinants of and solutions to the identified public health issue?                     |
| 3. | Who needs to be involved in the partnership to ensure that the values driving the research are respected in the planning and implementation of the research?   |
| 4. | Who needs to be involved in the partnership to ensure that the research results will be translated into practice and action?   |
| 5. | Who needs to be involved in the partnership to ensure that the research can be implemented with a balance of scientific integrity, social relevance, and cultural relevance?                             |
| 6. | Who needs to be involved in the partnership to ensure that the utilization of resources and assets from the community of interest are maximized during each phase of the participatory research process? |
| 7. | Who needs to be involved in the partnership to facilitate sustainability of the (a) research products, (b) capacity, (c) relationships, and (d) infrastructure?  |
| 8. | Which other stakeholders could be involved to help the partnership achieve its goals and objectives without compromising its values?   |

(e) individuals who operate at an administrative or political level and typically interface with service providers and staff rather than with end users or end users' interpersonal networks—including policy makers, executive directors, financial officers, and program administrators (administrators). If participants represent more than one group, it is important to clarify which hat they are wearing in each situation.

After identifying the potential range of partners, the next step is to specify the optimal mix. To assist, we have distilled eight questions from the literature. These questions (see **Table 2**) seek to balance the benefits of heterogeneity in the partnership with the challenges resulting from status and power differentials between diverse constituents. As Israel suggests (50), such differentials may make it more feasible for academic partners to work with less heterogeneous partners. The optimal mix should favor establishing and maintaining group processes that promote equitable participation, trust, and respect among partners. Given that partnerships evolve (discussed below), the eight questions should be answered at the engagement and formalization stages of the partnership and then revisited as the partnership progresses.

### How Should They Participate?

Equal participation of academic and nonacademic partners is the ideal for many PR approaches to help partnerships balance scientific excellence with social and cultural relevance; foster ownership, capacity building, and empowerment of nonacademic partners; and translate research knowledge into action. This democratic ideal emphasizes the unique strengths, complementary expertise, and shared responsibilities of academic and nonacademic partners who are engaged “in a joint process to which each contributes equally” (56). The hard-won lessons of PR suggest that achieving equal participation and power can be difficult (131, 135). A recent systematic review of CBPR found only 4 of 60 CBPR studies demonstrated community participation across all research phases (130). Another review found none of 46 practice-based research networks reported full engagement of patients in research (142). Given the challenges to realizing equal participation, the term equitable participation has been coined to guide academic and nonacademic partners' involvement in the research (40, 43, 56, 84).

How much and in what phases academic and nonacademic partners should participate depends on where the interests, expertise, and



energy of the partners reside; what is negotiated; and the extent to which partnership and project governance structures have made provisions to support the agreed on participation level. The upper bound of participation occurs when those affected by the issue remain actively involved in all PR phases. Within this fully democratic model, academic and nonacademic partners codirect each phase of the PR research process. Despite the difficulties in attaining this ideal, excellent examples are available, including research with community residents, medical and social service providers in the Chicago Southeast Diabetes Community Action Coalition (34), and the Hualapai community on youth wellness (125).

Equitable participation also extends to community-directed or controlled research, where decision making is shared but under the guidance of community partners (12, 22, 112) or driven by community organizations with consultative input from researchers (21). Therein, academic and nonacademic partners negotiate their participation so that end users, service providers, and administrators take greater responsibility for research decision making. This type of PR is strongly aligned with the indigenous sovereignty movement (21, 47) and applications of empowerment evaluation that encourage self-determination and self-evaluation (30) and grassroots leadership of community organizations (20).

Experience suggests that in some situations, nonacademic partners have limited time, expertise, or interest to contribute to some technical and labor-intensive components of the research process, but they want to shape the research questions, review and approve the research protocol, and participate in the interpretation and uptake of results (16, 63, 70). To ensure mutual respect and equitable participation, academic researchers should refrain from insisting that nonacademic partners participate when they do not wish to do so. Thus, the lower bound of participation in a PR project involves engaging nonacademic partners at least at the project's front end, in defining or refining the research

questions or otherwise contributing to the study direction, and at the back end, in interpreting and applying the research findings (43). This lower bound must not be used, however, as an excuse for less participation; instead, nonacademic partners must at least be given the opportunity to participate in all phases.

In summary, the literature suggests that equitable partnerships are defined by gradations of shared responsibility that are negotiated among academic and nonacademic partners and supported by open and flexible decision-making environments (104, 134). Participation can be seen to represent a spectrum with different partners having more influence at different points in project functioning.

## HOW ARE PARTNERSHIPS INITIATED AND HOW DO THEY EVOLVE?

Because conflict and tension are normative in partnerships, maintaining partnership integrity requires the use of effective group processes (134). We therefore reviewed literature discussing partnerships to uncover the stages of PR partnerships (10, 81, 97, 134), key partnership activities (27, 53, 77, 83, 97, 104), and potential trouble spots (12, 17, 53, 78, 83, 85, 131). These are presented in detail in **Table 3** and discussed below. The four partnership stages are fluid and overlap when new partners join and when a partnership supports multiple research projects simultaneously or in succession (54, 83).

### Engagement

Regardless of whether the impetus for the PR comes from the academic (34, 85, 107) or nonacademic partners (11, 70, 79), all partners need to discuss issues openly and respectfully to achieve consensus on the research through a colearning and reflexive process that addresses the needs of the intended beneficiaries and builds on the strengths of the

**Table 3 Key partnership activities to support research and their associated challenges, according to partnership stage**

| Partnership stage | Key activities   | Challenges  |
|-------------------|--|---|
| Engagement        | <ul style="list-style-type: none"> <li>● Identify community of interest</li> <li>● Get to know the setting, culture, and people</li> <li>● Identify leaders and develop relationships</li> <li>● Conduct environmental scan</li> </ul>   | <ul style="list-style-type: none"> <li>● Establishing trust and respect</li> <li>● Establishing a shared purpose or consensus on issue to be explored</li> <li>● Balancing cultural humility with technical humility</li> <li>● Overcoming communication difficulties</li> </ul>  |
| Formalization     | <ul style="list-style-type: none"> <li>● Address ethical concerns</li> <li>● Establish/revise<sup>a</sup> joint decision-making agreement</li> <li>● Establish/refine<sup>a</sup> mission or vision and operating principles</li> <li>● Define/refine<sup>a</sup> organizational structure and operating norms</li> <li>● Identify partners to maximize collaborative advantage</li> <li>● Develop/strengthen<sup>a</sup> leadership</li> <li>● Develop/refine<sup>a</sup> change model and monitoring system to assess change indicators</li> </ul> | <ul style="list-style-type: none"> <li>● Maintaining trust and respect</li> <li>● Ensuring sufficient time to develop a partnership</li> <li>● Identifying optimal mix of partners to implement the vision</li> <li>● Overcoming tensions between founding members and joiners</li> <li>● Providing adequate time and resources for capacity building</li> <li>● Overcoming power imbalances</li> <li>● Working amid ethnic, cultural, social, and organizational differences</li> <li>● Working toward equitable distribution of resources</li> <li>● Clarifying direction and governance of the project</li> <li>● Ensuring compatibility of active participation of the self-determined community with the ethical requirements of institutional review boards</li> </ul>  |
| Mobilization      | <ul style="list-style-type: none"> <li>● Hire and train staff</li> <li>● Manage budget</li> <li>● Establish quality control for data collection</li> <li>● Make provisions to enable participation</li> <li>● Build in mechanisms for capacity building through mentoring, workshops, and training</li> <li>● Acquire resources for sustainability</li> <li>● Document progress</li> <li>● Feedback information on the partnership's capacity to manage the research</li> </ul>  | <ul style="list-style-type: none"> <li>● Maintaining trust and respect</li> <li>● Resolving insider-outsider tensions</li> <li>● Having infrastructure support to implement research in nonacademic settings</li> <li>● Securing resources for capacity building and training nonacademic partners</li> <li>● Carving out time for academic partners to maintain research activities while developing local capacity and maintaining a local presence</li> <li>● Finding time for nonacademic partners to support research while delivering services and programs</li> <li>● Overcoming local instability and deep-seated powerlessness</li> <li>● Garnering technical assistance and resources to support activities</li> <li>● Maintaining “community” participation</li> <li>● Overcoming differences among partnering organizations' mandates, cultures, infrastructure, resources, and populations served</li> </ul> |
| Maintenance       | <ul style="list-style-type: none"> <li>● Feedback research results to partners</li> <li>● Acquire additional resources, if not already secured, to move knowledge to action</li> <li>● Refine plans to ensure sustainability of research, research products, the partnership, and capacity</li> </ul>  | <ul style="list-style-type: none"> <li>● Maintaining trust and respect to foster sustainability</li> <li>● Sustaining core funding</li> <li>● Dealing with reward structures that do not match partners' needs (e.g., service delivery organizations are rewarded for services, not for supporting PR)</li> </ul>   |

(Continued)

**Table 3** (Continued)

| Partnership stage | Key activities   | Challenges  |
|-------------------|--|---|
|                   | <ul style="list-style-type: none"> <li>• Revisit composition of the partnership to enhance sustainability</li> </ul> | <ul style="list-style-type: none"> <li>• Ensuring capacity building for nonacademic partners to do research</li> <li>• Gaining support from funders to help build the fiduciary capacity of community-based organizations to serve as lead agencies on projects</li> <li>• Demonstrating accountability to justify continuation</li> <li>• Sharing limited resources (inequity in receiving benefits strains relationships)</li> <li>• Maintaining morale and energy when funding is uncertain</li> <li>• Having time and resources to translate knowledge to action</li> </ul> |

<sup>a</sup>Multiple terms (e.g., develop and refine) are used in some stages to highlight that new partners and projects may be added to existing partnerships and may require adjustments to existing arrangements.

nonacademic partners (57, 84, 134). Taking the time to become familiar with and understand the context, the people, their culture, and priorities cannot be sidestepped without compromising the fragile foundations of mutual trust and respect (3, 146), which, if violated, can hamper methodological quality (131, 135).

### Formalization

Acquiring funding often leads partnerships to formalize. This involves expanding membership and establishing operating norms, principles, and an organizational structure. Partners establish parameters defining equitable participation: Who is involved and how much is initially negotiated at this stage. These parameters may be codified (3, 27) to protect participants from potential harms and ensure respect for the intended beneficiaries (91, 115, 139). Engaging partners in decisions on what data will be collected, how it will be collected, and how the project will be governed (including managing the budget, hiring and training staff, and facilitating capacity building) incrementally builds ownership and commitment and fosters empowerment (66, 90, 107, 125). When agenda-setting activities dovetail with formalizing new partnerships, it can take

12 months or longer (78, 93, 146). Otherwise, formalizing the partnership can consume the first six months of a project (54).

### Mobilization

The ease of implementing activities during mobilization is influenced by how adequately previous stages have addressed their component activities and fostered mutual respect and trust. Many partnering organizations house project offices, hire and train staff, and manage budgets (20, 66, 90, 98). Some partnerships mentor community researchers (104, 125), support community members in taking a leadership role in the partnership (4, 34), and advocate for the health issue in the broader community (79). These activities embed the research within the system the study is intended to benefit (97, 109), facilitate ongoing capacity building, empowerment, and ownership (11, 30, 93), and enhance sustainability of the partnership and its products (87). Developing a system to monitor progress on intermediate outcomes of capacity building, empowerment, and ownership further reinforces their importance and enhances project accountability insofar as their relationships to sustainability and project impact are made explicit.

## Maintenance

Maintenance involves sustaining the relationships, the infrastructure to support the partnership, the capacity-building process, and the products of the research (53). Ongoing investment, commitment, and ownership of intended users and decision makers in the research products are essential to sustain the partnership: If the research is not seen as relevant, there will be little motivation to continue working in the partnership (3, 79, 93). Consequently, partnerships (3) and funding agencies (86) need to invest early and heavily in capacity development to maximize the chances of sustainability.

## WHAT ARE THE CORE ELEMENTS OF PR?

Irrespective of the drivers for the research, the presence of mutual respect and trust among partners is essential to support capacity building, empowerment, and ownership. Additionally, capacity building, empowerment, and ownership separate PR from other forms of research that are collaborative or action oriented but not participatory.

## Mutual Respect and Trust

The integrity of partnerships rests on the presence of mutual respect and trust, both of which are fostered in decision-making environments that support diversity and allow partners to express and accommodate their different points of view through ongoing, open, and honest dialogue (3, 84, 134). Effective leadership, a strong predictor of partnership synergy, facilitates this type of communication (140). Building mutual respect and trust takes time and patience and, even once established, can never be taken for granted (77, 83, 134). Despite commitment to a shared purpose, partners often have different educational, cultural, racial, ethnic, and social backgrounds and areas of expertise, and they represent organizations, institutions, and agencies

with diverse agendas, mandates, and reward structures (14, 66, 117, 135, 146). These differences shape power dynamics and influence whose needs and interests are addressed by available resources and opportunities. Therefore academic and nonacademic partners must use critical self-reflection to understand how status and privilege impact partnerships and to have a sense of cultural humility (14, 51, 85, 135) and overall humility toward all partners (102). Additionally, partners need to respect each other's time and expertise by balancing socially, historically, and culturally rooted concerns against the need to accomplish research tasks (40).

## Capacity Building, Empowerment and Ownership

Partnerships need to actively create conditions conducive to the development and maintenance of capacity building, empowerment, and ownership. These conditions include a climate of mutual respect and trust, involving nonacademic partners in decisions about how resources are used and who is enabled to engage in opportunities and to lead, manage, and organize PR efforts. As illustrated by Fawcett's framework for collaborative empowerment (28) and Fetterman's (30) empowerment evaluation, communities and organizations require capacity to take collective action on their health issues. Capacity develops according to stages of readiness and reflects the potential (e.g., knowledge, skills, networks) of an organization, community, or other partner to address health issues that matter to it (36). The most effective empowering strategies enable and reinforce authentic participation, autonomy in decision making, and sense of community (132). Raising awareness about the root causes underlying health issues is a key aspect of engaging end users and other stakeholders in research because, consistent with the emancipatory ideal of CBPR, "knowledge is power" (96) and can galvanize people to act (11, 58, 87, 129, 137). Ownership among nonacademic partners—the extent to

which nonacademic partners carry responsibility for directing core functions of the partnership and its research activities (30)—must be supported from the engagement phase of the partnership (**Table 3**) or there will be little to sustain the effort beyond grant funding (53, 83).

A critical issue resides in the conceptual alignment of capacity building, empowerment, and ownership. Some frameworks conceptualize either empowerment (28) or capacity as the higher-order construct (36) and nest the other construct and ownership as subdimensions. This lack of conceptual clarity is problematic from an accountability perspective and needs clarification if the merits of PR are to be systematically assessed in relation to targeted health outcomes.

### Accountability and Sustainability

Academic and nonacademic partners have a responsibility to each other and their funders to account for how their project will achieve research objectives (30). Because the absence or loss of funding is identified as a major barrier to sustainability (53, 87), it is essential to ensure that funders have sufficient justification to continue funding by demonstrating ongoing project accountability through measuring intermediate outcomes of capacity building, ownership, and empowerment and making explicit their link to ultimate research outcomes and public health impact (26). Critical reflection on such information also helps partners understand how the partnership processes influence research outcomes and where adjustments may be needed to remain consistent with partnership goals. Tools to enhance accountability in PR include theory of change models (26), logic models (101), Getting to Outcomes (30), and health program-planning models such as Precede-Proceed (42). Use of such tools will strengthen accountability by building a knowledge base from which best processes for PR can be identified (38, 42).

Sustainability involves maintaining (*a*) the partnership, (*b*) its capacity, (*c*) infrastructure, and (*d*) research products (53). Case-study evidence suggests that inattention to the core elements of PR can compromise sustainability (17, 53, 131). Engaging the community of interest in the partnership and considering sustainability in the design of participatory efforts can enhance the likelihood that the partnership will continue and that research results will be translated into action and institutionalized (68, 87, 93, 112). With limited funding identified as a major barrier to sustainability, this upfront consideration is becoming even more important (53, 87).

### WHAT IS THE ADDED VALUE OF PR IN EACH OF THE RESEARCH PHASES?

Research projects progress through the phases of (*a*) shaping the purpose and scope of the research, (*b*) implementing the research and considering contextual factors, and (*c*) interpreting and applying the research outcomes. The added value of PR for academic and nonacademic partners within each of the three phases is detailed in **Table 4** and summarized below.

#### Shaping the Purpose and Scope of the Research

Consistent evidence demonstrates that insider knowledge can enrich academic partners' understandings of the needs, priorities, and health concerns of communities, organizations, and the public health system (79, 85, 137) and lead to refined and new research questions (20, 55, 100). Engaging with nonacademic partners in shaping the research purpose has the advantage of enhancing contextual readiness for research implementation (97). PR approaches enhance the relevance and importance of the research for nonacademic partners' needs and circumstances (34, 55, 70, 74, 100).

**Table 4 The potential added value of participatory research approaches across the three phases of the participatory research process**

|   | Added value for academic partners  | Added value for nonacademic partners   |
|---|--|--|
| Shaping the scope and purpose of the research           | <ul style="list-style-type: none"> <li>• Enriched understanding of health issues, especially politicized and sensitive issues</li> <li>• Refined and new research questions or hypotheses that address local concerns</li> <li>• Enhanced local ownership of research enhances community or organizational readiness to implement research protocol</li> </ul>   | <ul style="list-style-type: none"> <li>• Enhanced relevance and importance of research questions to the organization, community, or public health system</li> <li>• Research is responsive to the community of interest</li> <li>• Initiation of ownership, empowerment, and capacity building through active participation in the research</li> </ul>   |
| Research implementation and context                     | <p>Contextual advantage:</p> <ul style="list-style-type: none"> <li>• Enhanced fit of research activities with the context in which the research activities are implemented</li> <li>• Removal of barriers to implementing research activities through nonacademic partners' support for and ownership of the research</li> </ul> <p>Research quality:</p> <ul style="list-style-type: none"> <li>• More appropriate study designs, methodologies, methods, or measures for the population and setting</li> <li>• Reduced reporting bias from rapport between "community" data collectors and study participants</li> <li>• Enhanced recruitment and retention rates of study participants strengthen sample representativeness and generalizability and transferability of findings</li> <li>• Higher response rates enhance the statistical power of quantitative analyses and interpretive power of qualitative analyses</li> <li>• Enhanced cultural validity and reduced measurement error and misinterpretation of interview questions because concepts, measures, and questions are culturally congruent</li> </ul> | <p>Contextual advantage:</p> <ul style="list-style-type: none"> <li>• Research is less disruptive to implementing contexts</li> <li>• Enhanced credibility for other activities due to participation in PR projects</li> <li>• Linkage of study participants with needed health care resources by treating research as awareness building</li> <li>• Ethical agreements negotiated with academic partners address concerns of the community of interest</li> </ul> <p>Capacity, empowerment and ownership:</p> <ul style="list-style-type: none"> <li>• More targeted and efficient planning and problem solving</li> <li>• Strengthened sense of ownership through active participation in research activities</li> <li>• Increased capacity of nonacademic partners to do PR</li> <li>• Acquisition of specialized research knowledge, skills, and experience</li> <li>• Economic development through employment opportunities and local resource utilization</li> <li>• Acquisition of management and leadership skills</li> <li>• Development of decision-making skills</li> </ul> |
| Interpretation and application of the research outcomes | <p>Research quality:</p> <ul style="list-style-type: none"> <li>• Enriched interpretation of quantitative and qualitative research results from the integration of multiple perspectives</li> </ul> <p>Research capacity:</p> <ul style="list-style-type: none"> <li>• Enhanced capacity of faculty and students to do PR</li> <li>• Enhanced social and cultural sensitivity of faculty and students to work with marginalized and hard-to-reach populations on sensitive topics</li> <li>• Stronger alliances between academic and nonacademic institutions</li> </ul>   | <p>Capacity, empowerment, and ownership:</p> <ul style="list-style-type: none"> <li>• Timely feedback of research results to nonacademic partners and the community of interest</li> <li>• Enhanced capacity, empowerment, and ownership from participating in research dissemination and translation</li> <li>• Enhanced understanding of health problems, their root causes, and solutions can galvanize people to act</li> <li>• Increased capacity for health promotion</li> <li>• Enhanced media and educational capabilities</li> </ul> <p>Instrumental use of scientific knowledge:</p> <ul style="list-style-type: none"> <li>• Enhanced cultural and contextual relevance of developed interventions, program planning, and action</li> </ul>   |

(Continued)

**Table 4** (Continued)

|   | Added value for academic partners  | Added value for nonacademic partners  |
|---|--|---|
| Interpretation and application of the research outcomes | <p>Dissemination and translation:</p> <ul style="list-style-type: none"> <li>• Ability to reach diverse audiences (e.g., academic, policy, practitioner, general public)</li> <li>• Potential to engage in political advocacy</li> <li>• Enhanced public exposure through media recognition</li> </ul> <p>Sustaining the research:</p> <ul style="list-style-type: none"> <li>• Potential for infrastructure to support ongoing research programs that provide solutions to identified community health issues (e.g., Centers for Disease Control and Prevention's Prevention Research Centers program)</li> </ul> | <ul style="list-style-type: none"> <li>• Creation of inventories, training manuals, and handbooks to inform practice</li> <li>• Improved formulation of policy recommendations and policy changes</li> </ul> <p>Participation:</p> <ul style="list-style-type: none"> <li>• Potential for higher intervention participation rates when end users are involved in intervention development</li> </ul> <p>Sustaining the partnership and research products:</p> <ul style="list-style-type: none"> <li>• More effective applications for funding and leveraging of resources due to established credibility and capacity</li> <li>• Augmented intersectoral mobilization of leaders, volunteers, agencies, institutions, and businesses catalyzed by participation in PR</li> <li>• Improved linkages among community-, state-, and federal-level agencies</li> </ul> |

### Research Implementation and Context

For academic partners, growing evidence from PR studies employing different designs, methodologies, and methods shows that PR can improve research quality by increasing recruitment and retention rates (60, 70, 73, 79, 145), reducing reporting bias (60, 70), and reducing measurement error from survey and interview questions that are not culturally aligned (55, 70, 90). These improvements emerge from nonacademic partners participating directly (e.g., as community researchers) and indirectly (e.g., offering strategic advice) in data collection, which enhances the fit of the research with the implementing context(s) (97). Nonacademic partners benefit primarily through the development of their capacity, empowerment, and ownership (11, 90, 107, 130) and from research protocols that are less disruptive to ongoing community or program processes (109). Given the history of distrust from hit-and-run research, nonacademic partners also have greater assurance that their ethical concerns will be addressed respectfully and that participants, intended users, beneficiaries, and stakeholders will be protected from potential harms (91, 115, 139).

### Interpretation and Application of the Research Outcomes

Key benefits to academic partners include enriched interpretation of research findings through integrating different stakeholder perspectives (58, 90, 95, 107, 125), the potential for wider dissemination and translation of research results (87, 95), enhanced research capacity for PR (97), and opportunities to train students in state-of-the-art PR approaches and community development (79, 104). For nonacademic partners, scientific knowledge can be applied to improve existing programs or to create new programs, practices, services, and policies (34, 119, 125, 128). Integrating stakeholder perspectives with research results can lead to research products that are tailored to meet the needs of implementing systems, implementers, and end users (125, 128, 130). Partnering organizations can also enhance their credibility and leverage additional resources by forming alliances with academic partners (97, 104).

To the extent that partnerships do not attend to the key activities associated with their engagement, formalization, mobilization, and maintenance (Table 3) and do not create conditions that support the core elements of PR (whether through inexperience

or institutional or political challenges), PR efforts may fail to achieve research quality and intended outcomes.

## THE STATE OF PR SCIENCE: RECOMMENDATIONS FOR RESEARCH AND PRACTICE AND CONCLUSIONS

### The State of PR Science

As discussed throughout this critical review, major advances have been made over the past decade in understanding the practice of PR. Such advances have enabled the development of the PR practice framework provided in this article. Process evaluation of partnerships and partners' reflective field experiences on critical issues, challenges, barriers, and facilitators associated with implementing PR approaches (53, 57, 84, 85, 117, 135, 146) have generated practical strategies and tools to strengthen academic and nonacademic partners' capacity for PR (26, 30, 42, 52, 88). Nonetheless, lack of consistency in the use and measurement of core process indicators and the lack of comparative case studies have limited progress in understanding how variation in implementing PR approaches relates to research outcomes.

Although presently no systematic reviews demonstrate that use of PR is more or less effective than are non-PR approaches for specific inquiries, a review of descriptive and etiological research suggests that PR has moved research forward by balancing scientific standards with social and cultural validity to (a) illuminate prevalence rates of health problems (80, 93, 116, 119); (b) identify needs and priorities of diverse communities of interest (53, 77, 87, 99); and (c) establish causal associations between behavioral risk factors, social and environmental risk conditions, and the health status of vulnerable populations (60, 70, 73, 79, 145).

The only existing systematic review of the effectiveness of PR approaches in intervention research, published in 2004 for the

Agency of Healthcare Research and Quality (AHRQ), concluded that there was insufficient evidence and too much variation in existing studies to establish effectiveness (130). Of the 12 intervention studies that had outcome data and that were fully evaluated, the four randomized-controlled trials (RCTs) revealed some modest but positive effects, whereas the eight non-RCTs showed mixed results or no effects (130). On the basis of our observations from the literature, caution is warranted when reviewing PR efforts in which research outcomes are translated into new policies, handbooks, and interventions without evaluating their effectiveness and impact on health outcomes. Notably, since the AHRQ systematic review was completed, several studies have reported positive intervention effects (33, 62, 72, 75, 79, 94, 105) and numerous additional publications are expected from recent PR funding calls by the Centers for Disease Control and Prevention and the National Institutes of Health (39).

Evidence suggests that PR fosters capacity. The AHRQ systematic review found that community capacity was enhanced for 47 of the 60 included studies (130). Our current critical review of descriptive, etiological, and intervention studies itemized capacity benefits for academic and nonacademic partners (see **Table 4**). Missing, however, is a conceptual framework to consolidate these capacities and to locate them in relation to empowerment and ownership.

Another issue requiring attention is the generalizability paradox: Increasing the relevance and specificity of research to communities of interest can reduce the generalizability of the research outcomes. The scientific literature with its emphasis on internal validity has been unable to recommend generalizable best practices for the many communities of interest that are typically underrepresented in the studies qualifying for systematic reviews (38). Rather than generalizing hard outcomes across unequivocal settings and populations, Green (38, 42)



suggests that combining research with theory and participatory approaches in particular settings can guide academic and nonacademic partners in identifying the best processes for planning a local intervention while adapting evidence to achieve the targeted outcomes.

Although PR approaches hold promise for eliminating health disparities and increasing quality and years of healthy life, academic and nonacademic partners engaged in PR continue to experience challenges, as outlined throughout this review. The current state of PR science and practice leads us to recommend strategic investments in four key areas—all of which need to be addressed if PR approaches are to be sufficiently institutionalized to overcome these challenges and achieve their full potential.

### Recommendations for Future Research

1. The new pool of studies reporting intervention effectiveness (33, 62, 72, 75, 79, 94, 105) combined with studies at or nearing completion (39) suggest that a future systematic review of PR effectiveness may be worthwhile.
2. To enhance accountability and to provide funders and peer reviewers with evidence that PR projects are progressing adequately toward outcomes, we must identify how variation in the core elements of capacity building, empowerment, ownership, and sustainability impacts health outcomes.
3. To strengthen the accountability of PR projects to achieve research outcomes, greater conceptual clarity is needed (*a*) among capacity building, empowerment, and ownership and (*b*) between capacity development and sustainability.
4. Given potential overlaps and distinctions between the different drivers for PR, it is important to determine whether there are patterns in best processes for PR according to driver.

### Recommendations for Funding of PR

1. Funding for descriptive, etiological, and intervention PR as well as for studying processes and refining tools for PR should be offered both through specific calls for PR research and within other funding streams.
2. Pilot, planning and feasibility grants should be made available to facilitate engagement of partners, partnerships, and development of feasible research plans prior to submission of funding for specific PR intervention studies. This will increase the likelihood that: nonacademic partners will have participated sufficiently in shaping the purpose and scope of the research, partnerships are operating effectively prior to the intervention study, and intervention studies can progress in a timelier manner.
3. Supplemental or tiered funding should be considered to facilitate translation of knowledge into action of PR projects that have achieved intended outcomes and whose partnerships are sustained to assist with translation of research products.
4. Infrastructure support, such as that provided by CDC's Prevention Research Center program (<http://www.cdc.gov/prc/>), should be made available to enable the initial development and sustainability of partnerships whose capacity to tackle other health issues has been strengthened through involvement in one or a series of PR projects.
5. Where appropriate and desirable by partnerships, funders should consider mechanisms for enabling nonacademic partners to host project offices, administer budgets and integrate research into their operating procedures.

### Recommendations for Education and Training of Academic and Nonacademic Partners

1. Training in CBPR, as recommended by the Institute of Medicine (49), is focused

primarily on the driver of social and environmental justice. To enable academic and nonacademic partners to address the drivers of self-determination and translation of public health knowledge to action, training should be expanded to include these approaches.

2. Faculty development workshops and continuing education credits should be made available to assist researchers who wish to learn about, become partners in, or themselves undertake PR or who may be asked to serve as peer reviewers of PR research proposals or manuscripts.
3. Certificate programs and workshops should be made available and/or supported by academic institutions and funders to develop nonacademic partners' core competencies in PR.

### Recommendations to Increase Institutional Support for PR

1. Some Schools of Public Health and other academic institutions have taken steps to modify their policies and procedures for tenure and promotion to recognize participatory researchers' contributions to service learning and community and organizational development and to account for the increased length of PR projects and for inclusive authorship lists that recognize many partners' contributions (18, 103). Faculty engagement in PR will likely grow as institutions increasingly understand the benefits of PR for enhancing researchers' long-term productivity and improving translation of research to ac-

tion and act accordingly to further reduce barriers to tenure and promotion.

2. Policies and procedures of institutional review boards typically support individual rights and protections and ethical principles of justice, respect for persons, and beneficence. PR raises ethical issues related to active participants, iterative and flexible research protocols, collective rights and protections, and ownership of data by nonacademic partners (92, 115, 139). Greater alignment is needed between current institutional review board policies and procedures and the ethical demands of PR.

### CONCLUSIONS

Our critical review of PR approaches in public health culminates in an integrative practice framework featuring five essential domains (**Figure 1**) that participatory partnerships may wish to consider to realize their full potential (**Table 4**). In disentangling the partnership process (**Table 3**) from the research process with attention to the optimal mix of partners (**Table 2**) and core elements and values (**Table 1**) undergirding PR applications, this practice framework provides partnerships with a structured process for designing, implementing, and evaluating their PR efforts to impact health outcomes. Advances to PR practice over the next decade will require establishing the effectiveness of PR in achieving health outcomes; linking PR practices, processes, and core elements to health outcomes; increasing PR education and training opportunities; and achieving greater support for PR approaches among funders and institutions.

### DISCLOSURE STATEMENT

The authors are not aware of any biases that might be perceived as affecting the objectivity of this review.

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**Errata**

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