Participatory Research in Development of Public Health Interventions

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What this report adds:
Community-based participatory research (CBPR) engages community members at all phases of research, instilling community ownership of both the process and the product. This report reviews the evidence on CBPR and concludes that there is not yet clear evidence supporting this approach. However, the effectiveness of CBPR may be improved if users recognize its potential advantages and disadvantages.
Introduction
The relative ineffectiveness of many public health interventions, particularly those targeted toward disadvantaged groups, combined with the disproportionate burden of excess death and disease borne by these groups, has created a great need for more effective targeted interventions. The vast majority of excess death and illness is preventable; for example, in 2002 African Americans had nine times as many years of potential life lost due to homicide than did non-Hispanic whites, and twenty-four times the incidence rate of gonorrhea. The elimination of health disparities such as these is one of three overarching goals of Wisconsin’s State Health Plan.

Addressing these disparities requires a concentrated effort to generate new knowledge about health behaviors in specific populations, to “disseminate culturally and linguistically appropriate health information,” and to bridge the continued “gulf between ... knowledge and its application.” Therefore, developing more effective, community-appropriate public health interventions is a top priority.

One potential method for achieving this goal involves the use of community-based participatory research (CBPR). CBPR has been advocated for its base in social justice and its ecological, collaborative approach. A consensus definition of CBPR has yet to be attained, however, and there is little evidence base available to evaluate its impact. This paper will attempt to define and characterize CBPR, briefly discuss its advantages and disadvantages, and review the evidence base for its use.

Definition
Fundamentally, CBPR is a collaborative partnership between researchers and community members. Rather than outside researchers working alone in community settings, CBPR engages community members at all phases of the research, instilling community ownership of both the process and product. CBPR’s approach involves casting a wide net in recruiting participants and involving them in every step, including project design, implementation, analysis, and dissemination of results. CBPR typically uses a comprehensive ecological model, studying issues at a population level and taking social and economic contexts into account.

In traditional research, there is often a lack of connection between obtaining and using information. Some epidemiologists assume that it is the responsibility of others, specifically policy makers and public health advocates, to incorporate epidemiological findings into health promotion and disease prevention programs and policies. This view is based on an emphasis on scientific rigor and objectivity, as the journal Epidemiology sums up in its guidelines: “opinions or recommendations about public health policy should be reserved for editorials, letters, or commentaries, not presented as the conclusions of scientific research.” CBPR, in contrast, aims to intertwine research and intervention: “action is part of the research process itself.” It is inherently political, both as a means to an end and as an end in itself, reflecting its basis in social justice and democratic participation.

Other key elements of CBPR include cultural relevance and linguistic appropriateness. CBPR also emphasizes sustainable improvements in community health through capacity building and organizational learning: “a goal is for the scientist to pass skills to the community participants” so that the effects of the project continue when the researchers are gone.

Example
The Healthy Eating and Exercising to Reduce Diabetes (HEED) project, designed to address obesity and diabetes in African Americans in Detroit, illustrates many elements of CBPR. Consistent with the concept of community ownership, the project was “initiated by residents of Detroit’s east side who identified diabetes as a priority concern.” A community member was
hired as project coordinator, and community residents with experience as personal trainers, caregivers, youth leaders, and community organizers participated in training sessions to become project “advocates.” The advocates then developed interventions with the support of the steering committee. The academic researchers served mainly as consultants and observers to document the process.

The project took an ecological view of diabetes and obesity, including “social and economic policies, [and] social and physical environments.” Considerations included physical and financial access to healthy foods, public subsidies of particular food products, residential segregation and its effects on food access and “safe places in which to exercise,” and cultural views of nutrition and exercise. Accordingly, the intervention was multi-faceted, involving training in reading nutrition labels, demonstrations of culturally appropriate recipe modifications, development of weekly walking clubs, and the creation of a “monthly fruit and vegetable minimarket at a community site.”

Fusion of research and intervention is evident in the program’s iterative cycle of intervention and evaluation, which was done through community surveys and direct feedback from the advocates and community members. This led to real-time program changes, such as the addition of a component of linking community members to health services for diabetes management. This project also shows the long-term commitment required in CBPR, noting that “these relationships have been sustained over years.”

Pros and Cons
The potential benefits of CBPR are numerous (Table 1). Perhaps most significant is the potential for improved health in targeted populations: working collaboratively with the community may create more realistic and effective interventions. Most public health issues have multiple risk factors; CBPR’s ecological approach, involving multiple interacting factors, might provide more useful and applicable data than studies with more limited scopes. Similarly, a problem with many causes cannot easily be addressed from any one angle. The multi-pronged approach of CBPR, involving as many community members and organizations as possible, may improve large-scale results.

Table 1: Potential advantages of CBPR

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<th>Advantage</th>
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<td>Improved efficacy of public health interventions in specific populations</td>
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<td>Better understanding of the epidemiology of multi-factorial diseases</td>
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<td>Creation of multi-party interventions that are better designed to address multi-factorial diseases</td>
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<td>Bridging of the gap between public health knowledge and implementation</td>
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<td>More sustained results</td>
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<td>Capacity building for participants and community-based organizations</td>
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<td>Increased trust between researchers and communities</td>
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As mentioned above, the “action research” element of CBPR aims to improve use of existing public health knowledge. CBPR’s focus on community involvement may also lead to more lasting and sustainable results. CBPR may produce less tangible benefits as well, such as building local problem-solving capacity. Disadvantaged communities are often wary of researchers, based on previous experiences that have left them feeling exploited. CBPR might help to increase the trust and strengthen the relationship between these groups.

There are also several disadvantages inherent to CBPR (Table 2). Program designers might balk at the mingling of research and activism; many researchers feel uncomfortable participating in an area in which they are neither trained nor, perhaps, directly interested. Data gathered may be considered lacking in scientific rigor because it was not obtained by an objective third party.
Table 2: Potential disadvantages of CBPR

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<th>Potential Disadvantages</th>
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<td>Decreased scientific rigor</td>
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<td>Ambiguous role of individual funders/grantees</td>
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<td>Increased funding requirements</td>
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<td>Long-term commitment</td>
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<td>Time-intensive</td>
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<td>Delayed results</td>
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<td>Results not easily assessed by traditional methods</td>
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<td>Shared control of project</td>
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There are funding concerns as well. The multi-party aspect may facilitate funding by allowing for multiple sources, but "funders may face difficulty in defining their own role in relation to such partnerships." CBPR projects may require higher budgets, since they require recruiting and training community members, compensating community members for their time and expenses (transportation, child care, etc), and initial investments in community capacity building. However, CBPR can be significantly less expensive than randomized community trials.

Training and collaboration also make CBPR particularly time-intensive, due to the time required to build relationships, increase community capacity, and collaboratively design and implement a project. When the results accrue, analysis by traditional methods may underestimate the project’s value.

Another important consideration is the researcher’s shared control of the project. Rather than designing and carrying out an ideal project – one that fits with research interests, grant funding, career plans, and so on – researchers work with multiple other parties, many of whom have little or no background in research. Each of these parties brings their own set of priorities and values to the project.

Evidence Base
The evidence base for the effectiveness of CBPR is at best developmental. Despite numerous anecdotal and case reports of successful individual CBPR projects, there is little rigorous evidence that CBPR methods improve outcomes as compared to traditional research or interventions. This is due in part to the increased lag time between project initiation and results: programs may be ended before the change in outcomes is apparent. Project design is also a factor: simultaneously addressing multiple variables from multiple angles makes it difficult to “tease out the effects of the particular [element] being evaluated.”

Pooling data from CBPR projects is difficult due to the lack of universal agreement of its essential elements. Supporters of CBPR may feel that its benefits are underestimated because projects are included that failed to implement key elements, or that the outcome criteria being applied reflect a traditional research paradigm and are not applicable to CBPR. The situation is further complicated because many projects that might fit CBPR criteria are not identified.

Data available thus far offers little support to friends or foes of CBPR. There is no evidence to support claims that CBPR interferes with scientific rigor. Data support “enhanced intervention quality” and increased community involvement, but do not show relative improvements in health outcomes. A theme of these analyses, however, is that the data are too limited and varied to allow for a rigorous analysis.

Adequately assessing CBPR projects may require modifying evaluation criteria to increase emphases on qualitative assessments and intermediate outcomes, such as community participation, emergence of new community leaders, or a “deeper sense of community ownership,” rather focusing exclusively on health outcomes.

Conclusion
The limited effectiveness of public health interventions, especially those targeted at disadvantaged populations, has focused increased attention on CBPR. The methods of CBPR are supported both by common sense and the accumulated experience of decades of trial and error in
public health. However, CBPR also has important disadvantages and requires significant expense, making investments in this unproven field risky in a time of limited resources. A larger database of CBPR projects to analyze, combined with further development of appropriate assessment techniques, will help to clarify the cost-effectiveness and utility of CBPR. At this point, the lack of evidence to support CBPR may be out-weighed by its promise, and the demonstrated need for it in public health.

References Cited