PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
VOLUME 1: NO. 1 JANUARY 2004

STEP-BY-STEP: MAKING YOUR COMMUNITIES HEALTHIER

Representing Your Community in Community-based Participatory Research: Differences Made and Measured

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Suggested citation for this article: Katz DL. Representing your community in community-based participatory research: differences made and measured. Preventing Chronic Disease [serial online] 2004 Jan [date cited]. Available from: URL: http://www.cdc.gov/pcd/issues/2004/jan/03_0024.htm

As someone who cares about your community, you may see no particular reason to care about community-based research. Why not simply address what you know is important? Where does research come in?

Gertrude Stein is quoted as saying, "A difference to be a difference must make a difference." Often, the very best intentions and noblest of actions fail to make a difference. Or, perhaps worse, actions do make a difference, but the difference is not measured and is overlooked.

Investigators are good at measuring things, and every public health researcher receives formal training in robust evaluation methods. But researchers outside a community often lack the insights, the relationships, and the trust needed to make meaningful and lasting changes within the community.

Here, then, is our shared dilemma — and our shared challenge. Community leaders may be able to make differences they don't know how to measure. And academic researchers may know how to measure differences they don't know how to make! Each of us without the other is like the proverbial sound of one hand clapping.

Community-based participatory research, or CBPR, is a dedicated effort to measure the differences our actions make. To do this well, academic researchers and people like you — who know and care about a community — have the potential to become a new kind of whole greater than the sum of its parts.

For that relationship to be successful, CBPR must include well-planned partnerships between community advocates and researchers. So, how can community advocates identify researchers who are genuinely interested in working with the community to make real differences? Look for these clues:

Researchers begin their discussions with you by asking questions, rather than offering solutions.

Distinct from research conducted in a community (1), CBPR seeks to conduct initiatives with community members (2). CBPR is "a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities" (3).

Keys to successful CBPR include:

- developing relationships with members at various levels within the community;
- valuing diverse cultural perspectives;
- placing equal emphasis and importance on community knowledge and academic perspectives; and
- allowing for flexibility in research methods (2).

The functional unit of CBPR is the community-academic partnership. This relationship is influenced by factors such as community culture, the partners involved, and the

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initiative being conducted, and should consistently involve all partners in project planning, implementation, and analysis. In addition, researchers should disclose study methods and results throughout the initiative (4).

Also, good researchers will focus their questions on community assets, resources, and capacity, rather than barriers. From the beginning, they will formulate a plan to sustain the project's benefits within your community and impart ownership of the project to community members.

Recent trends in public health research and practice support a collaborative approach to health promotion and disease prevention efforts (1,2). Models in which communities determine their own priorities and participate in identifying suitable intervention methods — with academics lending their expertise in the role of partner — are increasingly valued (5,6). Accumulating evidence suggests that the most effective prevention strategies are those that actively engage the communities they are intended to serve (2,7,8).

It is, of course, possible that studies conducted for or in a community proceed without community support. Under such circumstances, however, researchers are apt to misconstrue priorities and overestimate, underestimate, or simply disregard community resources. When this occurs, beneficial research outcomes tend not to be translated into ongoing community programs, practices, or policies. Often, these studies lead to dead ends, lacking the means to produce real-world effectiveness.

Part of the reason such a disconnect exists between research and advocacy is that partnership between these two groups isn't exactly the most natural thing. Community groups often distrust academics, and, it's only fair to say, with good reason. Historically, public health research has been conducted almost exclusively by academic investigators. This approach has been faulted for its exclusivity and arrogance in relying on people from outside a community to identify the community's "problems" and the likely means of fixing them. The approach has also resulted in some of biomedicine's most shameful abuses of human subjects. But even when no such transgressions occur, the "for academics only" approach often leaves community members feeling used rather than involved. This history of distrust now presents an obstacle to effective collaboration. If you engage in discussions with potential academic researchers, make sure they can answer your question, "What's in it for my community?"

Another obstacle preventing widespread CBPR is that shared research takes a long time to cultivate and translate into publishable manuscripts, which makes academics reluctant to participate. Anything that slows down paper publication or grant acquisition threatens academic career advancement.

Researchers recognize the gap between measuring differences and making differences.

The frequent failure of researchers to make real-world differences is a matter of growing concern. One excellent example of both the great strength — and profound weakness — of academics on their own is the Diabetes Prevention Program (DPP), sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases.

This $174 million clinical trial demonstrated the great value of healthful eating and regular physical activity in preventing diabetes. Adults at high risk of developing diabetes were assigned to a non-intervention control group, a medication group (the drug metformin), or a lifestyle intervention that included dietary and physical activity guidance. The drug reduced the rate of diabetes by nearly one third, while the lifestyle intervention reduced it by an incredible two thirds! Two out of every 3 people in the lifestyle intervention group who would have become diabetic over the course of the study did not because of the treatment. Talk about a difference measured!

The trouble is, the real-world difference has not yet been made. The DPP lifestyle intervention worked only in the carefully controlled context of a clinical trial. The investigators don't yet know how to translate this benefit to real-world settings. In fact, the study sponsor is convening a conference early this year to address the challenge of translating the DPP benefits to real-world settings.

Researchers demonstrate a willingness to help you measure the differences you make.

An important principle underlying CBPR is that research is defined as the measurement of the differences a worthwhile project makes.

Examples abound of well-intentioned community groups setting out to make differences they neglect to measure. In

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2000, the Yale-Griffin Prevention Research Center was awarded a grant by the U.S. Department of Health and Human Services (9) to distribute competitive micro grants of $2,010 to community agencies addressing objectives specified in Healthy People 2010 (10). We distributed more than 100 grants to a wide range of groups dedicated to community health improvement. Researchers involved in the project, however, soon discovered that most grant recipients had no experience in evaluating and measuring such improvement.

The Connecticut Association for United Spanish Action (CAUSA; www.causainc.org), for example, is a respected nonprofit organization dedicated to enhancing the general well-being of the Hispanic/Latino population in Connecticut. Established in 1975, CAUSA has been lauded for its community service, but until recently, the impact of some of its healthcare programs had not been rigorously assessed. As a result of the Healthy People 2010 project, CAUSA is now collaborating with Yale-Griffin PRC investigators to develop a robust evaluation strategy for its recently funded diabetes prevention program.

Measuring differences is vital. Scientists can generate credible evidence only through evaluation and measurement, and evidence is important to advancing knowledge and procuring funds. Funders are increasingly adamant that we "show them the evidence" before they "show us the money!"

Researchers share control over financial resources and decisions with community representatives.

Money, of course, is an issue critical to developing CBPR. Make sure that you discuss funding arrangements with academic researchers right at the beginning. In addition, look for researchers who are prepared to share control over decisions on how to allocate funds throughout the course of the research project.

Some project details can only be defined when partners come together. Researchers, community groups, and funders must be willing to accept this open-endedness at the time of funding. This requires trust, and to some extent, a leap of faith.

CBPR is generating greater interest at the highest levels of public health research, practice, and policy, such as at the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health. The CDC has set an exemplary standard, fostering programs and providing funds to advance CBPR. Another example is the Connecticut Health Foundation (www.cthealth.org*), the largest private health foundation in the state, which has recently committed to funding community agencies that partner with academic researchers to ensure robust methods and measures. These examples show that successful measurement of differences increases incentive for funders to support CBPR. The message here seems to be, "if we build it, they will fund it!"

Researchers express commitment to a working relationship built on trust and equity.

CBPR is not a panacea. Organizing and working on multidisciplinary teams is challenging. Diversity of perspective and expertise is valuable, but it can also lead to diversity of opinion — as well as conflict. For CBPR to work well, all partners must commit to the project goals, remain well informed at each step of the research process, be willing to work through disagreement, and maintain mutual respect if consensus does not form easily. Project ownership and influence must also be shared equitably. Trusting relationships are essential, although they take time to develop.

Other community groups with whom the researcher has worked will be able to attest to the researcher's level of trust and respect. In addition, other groups can comment on the researcher's knowledge, flexibility, and commitment to lasting community changes. It is perfectly acceptable to ask your prospective research partner for references.

Conclusion

CBPR is challenging and time-consuming and requires a shift from old to new models of examining community programs and research. The stakes are too high for us to give in to our doubts and reservations. Making people healthier, making communities safer, and securing the resources needed to do what must be done will require that we make and measure meaningful differences. For this to happen, we need each other — it's that simple. One may hope that as changing times and changing funding mechanisms push and pull on academics and community members, we will increasingly find ourselves within arm's reach of each another. Before extending your hand, do your homework

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(See Table), and get to know your potential partners. Choose wisely and cautiously. But give this new opportunity your serious consideration. As partners, we can make the world a healthier place one community at a time — and gather the measures to prove it. The new rhythm of public health research can and should be driven by the sound of our hands coming together.

Acknowledgments

I am most grateful for the thoughtful insights of Margot Zaharek and Georgia Jennings, and for the technical assistance of Michelle Larovera and Jennifer Ballard.

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Tables

Table
Partnering with Academic Researchers: What to Look for

- Researchers begin their discussions with you by asking questions, rather than offering solutions.
- Researchers recognize the gap between measuring differences and making differences.
- Researchers demonstrate a willingness to help you measure the differences you make.
- Researchers share control over financial resources and decisions with community representatives.
- Researchers express commitment to a working relationship built on trust and equity.

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