

# Creating Partnerships, Improving Health:

## The Role of Community- Based Participatory Research



U.S. Department of Health and Human Services  
Agency for Healthcare Research and Quality  
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Health-related research studies may develop new treatments or find ways to prevent disease. But it can take years before these treatments become available in most clinics, doctors' offices, or community health centers. This is especially true for disadvantaged communities, even when they are the subject of the research.

There is a type of health care research that promises to directly benefit the people studied. This approach, **Community-Based Participatory Research (CBPR)**, actively involves the community being studied in the research.

### **How is CBPR Different and How Can the Community Make Sure That Its Involvement is Worthwhile?**

In CBPR, community-based organizations (CBOs) or groups, such as churches, church members, neighborhood organizations, community residents, and other social organizations, help researchers to recruit subjects. But they do more than that.

Community-based organizations play a direct role in the design and conduct of the research study by:

- Bringing community members into the study as partners, not just subjects.
- Using the knowledge of the community to understand health problems and to design activities to improve health care (interventions).
- Connecting community members directly with how the research is done and what comes out of it.
- Providing immediate benefits from the results of the research to the community that participated in the study.

In CBPR, community members are also involved in getting the word out about the research and promoting the use of the research findings. This involvement can help improve the quality of life and health care in the community by putting new knowledge in the hands of those who need to make changes.

## **Why Research Had to Change**

The goal of health-related research is to improve the lives of people in the community studied. In traditional research, the community is not actively involved in designing the projects. Often, when these projects run into problems—for example, the study takes a long time or costs too much money—community members, who frequently give their time and energy for no compensation, discover that they are left without information about the outcome of the research or any findings that can benefit the community.

Over time, when these problems occur, communities become suspicious of researchers. CBPR counters these suspicions by making the researchers and community groups partners from the early stages of the research.

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“To be effective, researchers need feedback from the community about its needs,” says Dr. Carol Horowitz of Mt. Sinai School of Medicine in New York. “It is important that community groups be clear about their priorities. It’s really common sense,” she says. “Don’t go into a community to fix something unless you’ve asked them what they need. You can’t fix people—you have to work with people.”

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## **Challenges That CBPR Partners Face**

More and more, the importance and promise of CBPR in health care is being understood by communities, universities, and funders. However, CBPR is still underused. Researchers who are

involved in CBPR have identified several requirements for its effective use. These include:

- The need to increase incentives for communities to get involved in CBPR.
- The need for communities to develop the ability (through skill building, training, and business development) to effectively partner with research organizations.
- The need to increase incentives for universities and research organizations to conduct CBPR and to seek partnerships with CBOs.
- The need to improve funding for such research and improve funding mechanisms to allow for community input.

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“Depending on the level of maturity of the community organization,” notes Richardo Guzman, Executive Director of the Community Health and Social Services Center (CHASS) in Detroit, “the impact of participatory research collaborations will vary. Such collaborations can help bring in needed funding, assist in developing proposals for new programs, and assist in developing comprehensive evaluations of community needs. Without CBPR, community groups often cannot do these things.”

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“Community-based participatory research, for us, is conducted by, for, or with lay people. In many instances, lay people’s involvement in research has had a profound impact on environmental health issues and social determinants of health,” says Khan Rahi, of the Washington, D.C.-based Loka Institute.

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## **How to Get Involved**

Community groups, whether established organizations or informal gatherings of individuals, that want to establish CBPR projects in their communities can do the following:

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## **A National Meeting on CBPR**

In November 2001, a meeting on community-based participatory research was organized by the Agency for Healthcare Research and Quality (AHRQ) and the W.K. Kellogg Foundation, along with other government partners. This meeting brought together researchers, funders, and leaders of community organizations to discuss ways to increase the use of CBPR in addressing health care problems. The meeting addressed the role of these groups in promoting CBPR. Recommendations are published in the meeting's summary report. The summary is available on AHRQ's Web site (<http://www.ahrq.gov/about/cpcr/cbpr/>).

Attendees at the AHRQ–Kellogg Foundation conference identified a number of priorities that needed to be adopted to improve participation by CBOs in CBPR:

- Combating a legacy of community mistrust of research.
- Reversing the severe underrepresentation of people of color and those from low-income backgrounds in health professions and research.
- Paying increased attention to resource sharing between universities and the communities.
- Ensuring that the entire community, not only powerful CBOs and “community gatekeepers,” are represented.

## **Supporting Community-Based Organizations**

The November 2001 meeting identified a series of actions that funders and colleges and universities should undertake to promote participatory research, and that will help link the research with the community:

- Recognize and highlight community assets and strengths (for example, view community members as advisers and experts).
- Provide real service to communities by addressing the community's needs.
- Build and maintain respecting, trusting relationships within/across the community. In particular, develop relationships with opinion leaders in the community.
- Sustain relationships beyond the research study itself.
- Include communities in planning the study.
- Welcome new participants into the discussion.
- Acknowledge and make use of existing community structures (for example, powerful CBOs and grass-roots groups).

These are also factors that CBOs should look for in a research partner or funder.

Finally, those attending the conference recommended the need for new roles for community members and CBOs in the research process:

- Community members should serve on academic institutions' Institutional Review Boards. (These boards rule whether proposed research on human subjects is ethically appropriate.)
- CBOs with successful, funded projects should guide CBOs who need help to become ready to become involved in participatory research.
- Funders should support forums for community leaders and CBOs to share experiences and learn about CBPR.
- Funders should involve community representatives in their grant-making process.

- Contact researchers at local universities.
- Contact funding organizations that support health care research.
- Become active on an Institutional Review Board (a group that oversees the ethical aspects of research on humans).
- Join a community research network.

## Resources:

### ***Community–Campus Partnerships for Health (CCPH)***

A national nonprofit organization that supports CBPR partnerships, CCPH maintains a Web site of CBPR resources, including definitions, principles, tools, reports and presentations, journal articles, syllabuses and course materials, Web links, electronic discussion groups, and more. It can be found on the Web at <http://futurehealth.ucsf.edu/ccph/commbas.html>.

CCPH’s biweekly e-newsletter, *Partnership Matters*, compiles timely announcements about CBPR grants, conferences, and publications. To subscribe, send e-mail to [ccphuw@u.washington.edu](mailto:ccphuw@u.washington.edu) or visit <http://www.ccph.info>.

### ***Community-Based Public Health Caucus***

This group, affiliated with the American Public Health Association, can be reached via e-mail ([cbphcaucus@umich.edu](mailto:cbphcaucus@umich.edu)). According to its Web site (<http://www.sph.umich.edu/cbph/caucus/>), this organization “is guided by the belief that Community lies at the heart of public health, and that interventions work best when they are rooted in the values, knowledge, expertise, and interests of the community itself.”

**For further information** about community-based participatory research, contact:

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## Two community perspectives

For the past 32 years, the Community Health and Social Services Center (CHASS) in downtown Detroit has provided health care and other services for poor and minority residents of that city. In the most recent year, the doctors at CHASS saw 6,500 people a month, mostly women of childbearing age and children. Ricardo Guzman, the center's executive director, describes the program as follows:

Community health centers such as CHASS have been slow to join together with university researchers because of barriers such as mistrust that kept the two groups apart, according to Guzman. Talks led to identifying common interests and allowed the development of an equal partnership. The community group made clear to the researchers that, "We in the community were not going to be involved in the project for research's sake unless some type of intervention was involved," he said.

The discussions led to a series of projects on diabetes in the Latino community served by CHASS. Over time, the interactions between the researchers and the community have built enough trust to get the health center and its supporters involved in collecting information that could lead to improved interventions in the community to reduce the risk or effects of diabetes.

The diabetes projects—such as those conducted through the REACH Detroit Partnership, funded by the U.S. Centers for Disease Control and Prevention—also created a stronger relationship between the city's Latino and African-American communities, both of whom suffer from a high incidence of this illness. Both minority communities realized that they could work together to get a larger impact, Guzman says.

Another supporter of CBPR is Khan Rahi, a community development organizer and coordinator of the Community Research Network of the Loka Institute (<http://loka.org>), based in Washington, D.C. Much of his organization's efforts have been to support local groups trying to solve environmental health problems. Rahi notes an Oklahoma group that began with a teenager who observed rashes and other problems in herself and others who had been exposed to lead in a childhood sandbox in her backyard. The local group took up the issue and attracted the attention of the Harvard School of Public Health, which did studies with the local community confirming the problem. This partnership with the community and Harvard University led to cleanups to reduce childhood lead exposure.

“This is the meaning of grassroots involvement,” says Rahi, “that issues come out of the community’s daily life.”



#### **A researcher's perspective**

Carol Horowitz, M.D., M.P.H., of Mt. Sinai School of Medicine in New York

City knows the difficulties of bringing research and its fruits to local communities. As the director of the East Harlem Diabetes Center of Excellence, she finds that she has to explain that research is not just drawing blood. The East Harlem Center began with a community health committee, and sought to raise awareness of diabetes in this predominantly minority community.

To reach the population with information on the disease, the Center sponsored salsa and merengue dances. It also commissioned street artists to bring diabetes awareness to the East Harlem residents. But the Center also conducted research—it surveyed 1,000 community residents to find out their knowledge about diabetes, and did a survey comparing the availability of healthy foods in East Harlem and in the adjoining neighborhood, the wealthy Upper East Side of Manhattan.

“We don’t have many strong, powerful community-based organizations [supporting us], so we’re working with senior centers, food pantries, and even individuals,” Dr. Horowitz says. “Anyone who wants to work in a community has to get out into it and meet people.”

Dr. Horowitz emphasizes the importance of health care outreach activities, which may not be publishable in research journals. There is money available for outreach on health care from foundations and government agencies, she notes. Researchers need feedback from the community about its needs, Dr. Horowitz says. It is important that community groups be clear about their priorities.



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