

SPECIAL ISSUE:***Three Models of Community-Based Participatory Research*****Janet Weiner, MPH**

*LDI Associate Director for Health Policy
University of Pennsylvania*

Jasmine A. McDonald, PhD

*Postdoctoral Fellow, Cancer Epidemiology,
Columbia University*

Summary: Community-based participatory research (CBPR) is a collaborative process between community-based organizations and academic investigators. It has the potential to make research more responsive to existing needs and to enhance a community's ability to address important health issues. But CBPR is often unfamiliar territory to academic investigators and community organizations alike. We interviewed CBPR investigators at Penn and community

leaders to ascertain best practices in CBPR and to compare academic and community perspectives.

A number of models of community-academic partnerships emerged, each with its own advantages and disadvantages. The perspectives of the investigators sometimes matched those of the community leaders, but diverged in important ways.

CBPR experiences: common themes, different models, lessons learned

Increasingly, active community participation in research is being recognized as essential to improving health outcomes in diverse populations. Community-based participatory research (CBPR) has the following features:

- It acknowledges the community as the primary unit of identity.
- It enhances and builds on the existing strengths of the community.
- It fosters collaborative relationships between the academic institution and community partners throughout the entire research process.

- Knowledge gained through the partnership is translated into specific action.

A key goal of CBPR is to enhance a community's ability to address important health issues through the development of effective interventions that can be maintained over time. Ideally, community stakeholders are actively involved in all phases of the research.

But CBPR initiatives vary considerably in their scope and success. In 2010, we conducted semi-structured interviews with four CBPR investigators at the University of Pennsylvania and three

community leaders to understand the barriers to, and facilitators of, CBPR partnerships. We elicited their views on the knowledge and skills needed to create and sustain these partnerships. The common theme emerging from the interviews was the need to develop relationships that go beyond individual research projects and to “stay at the table” when difficult issues (such as racism or classism) are raised.

We discern three models of CBPR through this investigation. These models differ in the scope of the research conducted and in the level of community involvement in each phase of the research. Some of the fundamental lessons, however, cut across these models and provide insight into how to establish and maintain a vibrant CBPR portfolio.

Model 1: single-theme collaboration between a university-based center and a community organization

One model is a **focused, single-theme collaboration** between a university-based center and a community organization. At Penn, this model is illustrated by the Center for Excellence in Environmental Toxicology (CEET) and its relationship with the Chester Environmental Partnership in Chester, PA. In this model we see a convergence of academic and community interests and shared goals.

Dr. Edward (Ted) Emmett, Professor in Occupational and Environmental Medicine at the Perelman School of Medicine, directs CEET’s Community Outreach and Engagement Core. Since 2005, he has worked with selected communities to address existing environmental health problems. He describes a basic approach to CBPR that consists of identifying a community group with a similar mission and developing relationships with its leaders. As a platform for ongoing community involvement, CEET established a Stakeholder Advisory Board, consisting of 15 people from local communities, one of which was Chester, PA, 15 miles south of Philadelphia. He identified the Reverend Doctor Horace W. Strand Sr. as a first point of contact in

Chester. In the early 1990s Rev. Strand was a major figure in the first environmental racism lawsuit, *Chester v. Seif* that went to the US Supreme Court and in 2005, he founded the Chester Environmental Partnership (CEP).

Dr. Emmett noted that successful CBPR must address an existing problem in the community. “Don’t go out with a particular research project in mind; go out around problems and look for solutions.” He also noted that trust is essential, and that relationships build over time. “You need people and apparatus to maintain relationships, like an embassy. Success in working with the community means research that is administered and communicated in a way that is comfortable for the community.” Because individual researchers may have little time for these extended activities, Dr. Emmett sees the need for “core” resources and people within larger center grants devoted to working with the community.

Dr. Emmett has used this approach to conduct a number of CBPR projects, including assessments of community exposure to industrial contaminants (perfluorooctanoates, or C8) in the Parkersburg, WV area, and an ongoing study of seafood safety

in the Gulf Coast region after the 2010 oil spill. The former project won the Community-Campus Partnerships for Health's Annual Award in 2008 for its success in reducing level of contamination in the community's drinking water and for its innovative "Community First" communication model, in which study results are released first to study participants and then to the broader community, instead of publishing study results in scientific journals and hoping the results trickle down to the community.

Dr. Emmett believes personal chemistry is key to successful CBPR partnerships. "You have to enjoy working together, and have good communication." But it also requires understanding the issue at a community level. "These are passionate people facing serious issues, and they will work with you if they respect and believe in you." Once respect is established, Dr. Emmett has found that people want to participate. "People want to tell us their stories. It's sort of cathartic and nurturing for them." However, he recognizes that researchers must get beyond theory and good intentions. "There should be money in it for the community. We need to incorporate them into grants."

Rev. Strand recalls the initial call from Dr. Emmett. He was open to collaboration, he says, because "academic institutions bring prestige

to the table that politicians can't ignore." He had no previous experience working with an academic institution, and greeted the overture with enthusiasm. "They have knowledge that's beneficial to us." Over time, Rev. Strand says, collaboration with CEET researchers has been positive. "They are sensitive to the needs of the community, and know how to blend in. They worked to empower us."

The partnership has been mutually beneficial. CEET has provided CEP with environmental health expertise on various health and environmental justice issues, and has participated in Chester's City Health Fair. It has developed mentorship programs in which Penn medical students visit Chester, attend a CEP meeting and have a small group discussion with Rev. Strand on environmental justice issues. Rev. Strand notes the importance of his participation on the Stakeholder Advisory Board. "It gives scientists insight and guarantees that there's a next stage to make change."

The partnership has also provided the community with resources it needed to address health issues beyond environmental ones. "We got a full-time support person from Penn who could work on other health problems important to this community, such as infant mortality, low birthweight, and sexually transmitted diseases," Rev. Strand said.

Model 2: targeted, area-based collaboration between academic researchers and a small group of community organizations

The second model is a **targeted, area-based collaboration** between academic researchers and a small group of well-established organizations in a community. At Penn, this model is illustrated by the Center for Community-Based Research and

Health Disparities (CCRHD) and its Triumphant Living Collaborative (TLC). Established in 2005, TLC creates community-driven research and produces programs designed to reduce the burden of health disparities among African

Americans in West and Southwest Philadelphia communities. TLC is collaboration among the National Black Leadership Initiative on Cancer (NBLIC), the Health Promotion Council of Southeastern Pennsylvania (HPC), the Southwest Action Coalition (SWAC), the Christ of Calvary Community Development Corporation, and Penn.

Chanita Hughes-Halbert, PhD directed Penn's CCRHD and had a three-year planning grant from the NIH to develop community-based programs. She came to Penn in 2001 and worked with Jerry Johnson, MD, to identify organizations with a health focus. Dr. Johnson is a longstanding Penn faculty member who had worked with many community organizations in the past. Dr. Hughes-Halbert felt that this existing connection was essential in overcoming the organizations' "trepidation" about working with Penn. Their concerns included being appropriately compensated for their time, and trusting the university.

Ernestine Delmoor, Chair of the Philadelphia chapter of NBLIC, echoes the importance of a comfort level with the investigator, rather than the institution. "No one has a relationship with the university. Bureaucracies are concerned about keeping themselves alive." Dr. Hughes-Halbert says she benefited from being new to Penn. "I wasn't part of the old boys' network." As she became acclimated to Penn, she began working with the NBLIC on a number of small projects. These preliminary steps allowed both parties to "test drive" their relationship and allowed Dr. Hughes-Halbert to get a feel for the "area" in this area-based collaboration.

Ms. Delmoor notes that collaborative relationships between researchers and community

groups evolve slowly. "CBPR has to naturally occur, you can't force that." A new researcher needs to understand the city. "You can't just say, hey people, come on. They have to develop trust in you."

Collaboration among TLC partners and the University is facilitated by an Executive Committee, which meets monthly to discuss results and strategies. Dr. Hughes-Halbert says that attendance at the Executive Committee meetings has varied, because of the time constraints of both Penn investigators and busy community leaders. Attendance has been better for the Health Intervention Subcommittee, which has met weekly to work out the details of programs as they are implemented.

The Collaborative conducted a needs assessment in 2006, where residents shared their health-related priorities through surveys and interviews. Dr. Hughes-Halbert explains that the community partners were involved in designing the questions and in analyzing the data, but were deliberately not included in recruiting participants. "Performing recruitment marginalizes them [the community]," she said.

The results of the needs assessment indicated that residents were most concerned about violence, diabetes, cardiovascular disease, and cancer. Since TLC organizations had existing expertise in cardiovascular disease and cancer, they developed educational programs to address these concerns:

- A Community Risk Education Program to educate residents about their risk for cancer and cardiovascular disease, which is being evaluated as part of a randomized trial; and
 - A Community Navigator Program to help residents improve access to cancer screenings.
- Dr. Hughes-Halbert notes that navigators,

funded at 20 hours per week, “are part of the community, live in the community, and now have developed extra skills to disseminate to the community.”

Ms. Delmoor judges the experience to be positive for all participants. “The community gives [Dr. Hughes-Halbert’s] research an edge. It provides her with credibility. In return, community programs are developed.”

Model 3: broad-based coalition of grassroots organizations

The third model is a **broad-based coalition** of formal and informal grassroots organizations. At Penn, this model is illustrated by the development of the Philadelphia Area Research Community Coalition, (PARCC), composed of 22 organizations, agencies and programs. Dr. Jerry Johnson, chief of the Division of Geriatric Medicine at Penn, is the academic leader of the coalition, which includes faith-based organizations, a health promotion council, a multipurpose social service agency, a federal health center, a YMCA, several small grassroots organizations, and three academic institutions.

Rather than focusing on a specific research project, or inviting a few organizations known for their experience in health research, education or delivery, Dr. Johnson and colleagues started with an open invitation to community organizations in West and Southwest Philadelphia and investigators interested in CBPR at all local academic institutions. More than 100 residents and organizational representatives attended an initial symposium, and of those, 40 attended a 2005 planning meeting that gave birth to PARCC. Of the 40, 22 member organizations gelled into PARCC after six months.

Dr. Johnson says that his previous experiences led him to question the traditional definition of CBPR, where the community is involved in all

phases of research. “Participation in all phases gets a little fanciful if not naïve.” He prefers a definition of CBPR in which community members participate in at least these three areas:

- (1) deciding what is to be researched;
- (2) advising on and interpreting results; and
- (3) disseminating results to the community.

Over a 2.5 year developmental process, PARCC established core work groups, a governance structure, operating principles, research training activities, community health education projects, and several PARCC-affiliated research projects. Dr. Johnson points to the following features as key to PARCC’s success: committed and trusted leadership, preexisting relationships, trust among members from the community and academia, research training, extensive time commitments of members to the coalition’s work, and rapid development of work group activities.

“The passion and time required do not allow this model to be for everyone,” Dr. Johnson says. NIH support from the Penn-Cheney EXPORT Center for Inner City Health enabled the developing coalition to hire an external community consultant who attended monthly meetings during PARCC’s first year and provided feedback after each meeting.

An example of PARCC-facilitated research is the CDC-funded Philadelphia Collaborative Violence Prevention Center (PCVPC), which

was planned with four PARCC organizations. A PARCC community representative serves as co-leader of each of four core centers. Community members have been instrumental in designing questionnaires, planning focus groups, and developing protocols and procedures for the center's research.

Dr. Joel Fein, principal investigator of the PCVPC, reflects on his experiences with PARCC and CBPR. "It's important to make a commitment to the community, with or without a grant." He sees CBPR as a two-way street. "They have the right to ask you for your expertise, just as you have the right to ask them."

He notes the importance of acknowledging and accepting the prior history of distrust between Penn and the community. Dr. Fein pinpoints three essential elements of healing pre-existing distrust: listen, follow through, and "stay at the table."

It is also important, he says, to bring "appetizers" to the table. "You need to build in more capacity than you have in the grant...sustainability means leaving something behind when you leave."

As part of PCVPC, Dr. Fein, Dr. Stephen Leff, and their colleagues from CHOP, Penn, Drexel and Temple Universities worked with Tom Henry,

Advisor to the Kingsessing Recreation Center and PARCC member, to develop and test an afterschool anti-violence program. Mr. Henry worked at Penn for 38 years and knows firsthand the history of racism, classism, sexism, and elitism that sometimes characterized relationships between Penn and its surrounding community. "When you mention the word Penn to the community, that's a tough thing. We don't trust Penn. It's an Ivy-League elitism thing." He notes that PARCC investigators have been willing to discuss and deal with issues of racism and classism. "If PARCC was not willing to deal with these issues, I wouldn't be involved with PARCC."

He believes that PARCC serves several useful functions. PARCC "put a structure in place where young investigators can come in" and learn about the community. "They have to understand where we are coming from," he says, because the community "has needs today, not tomorrow." He agrees with Dr. Fein about the importance of staying at the table. "It's all about relationships and trust and relationships that evolve over time." Mr. Henry also notes the pre-existing trust that Dr. Johnson had earned before PARCC. "I respect the fact that he won't walk away, and that he lets you voice your opinion."

Conclusions and insights into CBPR

The three models of CBPR—a focused, single-theme collaboration, a targeted, area-based collaboration between a university and a select group of community organizations, and a broad-based coalition of local universities and community groups built from the ground up—offer us insight into the recurrent challenges and competing visions of community-based research.

- Relationships that have been built within CBPR are years in the making, especially if there is base-level distrust towards the institution. PARCC is one model in which trust can be regained and new investigators can begin to collaborate with the community. However, PARCC is also the most labor- and time-intensive model to create and sustain.

-
- In some ways, CEET and the collaboration with CEP in Chester had fewer obstacles to overcome. Rev. Strand had no prior experience with Penn, and welcomed academic involvement because Chester had been neglected for so long. The distance from Penn (about 20 minutes) meant that Penn was considered less a neighbor and more of an outside expert. The targeted focus on one theme—how the environment affects the health of residents—may have facilitated the convergence of academic and community interests and the development of shared goals.
 - The Triumphant Living Collaborative grew out of relationships formed by Dr. Hughes-Halbert and community leaders over a few years. In contrast, the PCVPC was more of a crash course for Dr. Fein and the four academic institutions partnering around a violence prevention project. A broad-based coalition offers more opportunities for community participation, but also more challenges when disparate groups and researchers are brought together without prior knowledge or trust in each other.
 - Across models, successful CBPR partnerships leave something of value in the community. CEP in Chester gained a full-time employee who could work on other health issues as well as the core environmental research projects; TLC in West Philadelphia now has community navigators to help residents gain access to cancer screening; and PARCC has produced anti-violence programs for local teens. Rev. Strand emphasized that financial support of the community organizations was crucial to achieving the health goals of these partnerships.
 - Despite the ideal of having the community involved in all phases of the research (from study design to collecting and analyzing data, to writing and dissemination of results) CBPR investigators have found that the community doesn't want to be involved in all aspects. Community partners emphasize that their primary goal is to create sustainable programs to improve the health of the community, rather than to develop research expertise. There is little agreement on the community's role in activities such as recruiting research subjects. Although CBPR can be a framework for more successful recruitment and retention of study participants than traditional research, recruitment activities can also minimize the community's role as a full and equal partner.
 - Academic investigators cite time constraints and lack of infrastructure as the greatest barriers to community participation in CBPR. The community leaders, on the other hand, more often cite lack of trust and racism/classism as the greatest barriers.
 - Both academic investigators and community leaders cite money and trust as the greatest facilitators of community participation in CBPR. Respect—of the community's voice, its expertise, and its experience—emerged as one dominant theme. "It's always a learning process, maintaining respect and earning respect," a community leader noted.
 - The participants recognize the common theme of "The Table," where the circle of trust and test of commitment occurs. To be involved with CBPR, you must bring valuable things to the table, stay at the table, and you must share the table.
-

This Issue Brief was supported by a Clinical and Translational Science Award (UL1 RR024134) from the NIH.

The authors would like to thank all of the participants for their time, wisdom, and insight. Dr. Hughes-Halbert left Penn in 2012 to take a position at the Medical University of South Carolina.

*Published by the Leonard Davis Institute of Health Policy, University of Pennsylvania, 3641 Locust Walk, Philadelphia, PA 19104.
Janet Weiner, MPH, Associate Director for Health Economics, Editor
Dan Polsky, PhD, Executive Director*

Visit us on the web at <http://ldi.upenn.edu>

Issue Briefs synthesize the results of research by LDI's Senior Fellows, a consortium of Penn scholars studying medical, economic, and social and ethical issues that influence how health care is organized, financed, managed, and delivered in the United States and internationally. The LDI is a cooperative venture among Penn schools including Medicine, Nursing, Dental Medicine, Communication, Law, and Wharton, and the Children's Hospital of Philadelphia.

For additional information on this or other Issue Briefs, contact Janet Weiner (e-mail: weinerja@mail.med.upenn.edu; 215-573-9374).

© 2013 Leonard Davis Institute

Published by the
Leonard Davis Institute
of Health Economics
University of Pennsylvania

Issue Brief



Nonprofit Organization
U.S. Postage
PAID
Permit No. 2563
Philadelphia, PA 19104

3641 Locust Walk
Philadelphia, PA 19104-6218
215.898.5611
fax 215.898.0229
ADDRESS CORRECTION REQUESTED