

## Challenges of Conducting Community-Based Participatory Research in Boston's Neighborhoods to Reduce Disparities in Asthma

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**ABSTRACT** *Boston is one of the preeminent health care and research centers in the world, but for much of its urban core, these resources are largely out of reach. Community Based Participatory Research (CBPR) provides a model with the potential to bridge the gaps between its research prominence and the health of its residents. We report here two case studies of major research projects that were partnerships between universities in Boston and community based organizations and city agencies. The Healthy Public Housing Initiative (HPHI) and the Asthma Center on Community Environment and Social Stress (ACCESS) are projects that provide numerous lessons about the potential and challenges of conducting CBPR. Ensuring that the projects were true partnerships emerged as key issues in both, especially with respect to funding mechanisms and distribution of resources, although the nature of the challenges differed substantially in the two projects. We note that both academic and community partners may harbor stereotypes about the other and that generalizations about broad populations, academics or community members, may not apply well to everyone. Aligning objectives and expectations emerged as another key lesson. In HPHI, tension between service delivery and research was both a source of conflict and a source of creative development that led to divergent but interesting outcomes. In ACCESS, the tensions revolved more around community capacity building while attempting to build and maintain a large cohort for epidemiological investigations. We conclude that open and frank discussion and a transparent process upfront about project direction, finances, expectations, and other dimensions are necessary but not sufficient to address the inherent challenges in CBPR, and that even so, there are likely to be differences in perspective in such partnerships that require honest negotiation throughout the process of the project.*

**KEYWORDS** *Asthma, Health disparities, Boston, Community-based participatory research, Public housing, University-community partnerships*

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### INTRODUCTION

The front page story of the February 18, 2002 edition of *The Boston Globe* read "Hub's share of NIH fund tops in U.S."<sup>1</sup> Although this level of funding from the

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U.S. National Institutes of Health (NIH) represented a triumph for the research community of Boston, some people in the broader community immediately thought of how little difference it all made in the lives and health of the residents in public housing and the patients of community health centers.

Although Boston's research and teaching hospital infrastructure makes it a "Medical Mecca", residents who live in the shadows of these prestigious institutions display elevated risks of multiple diseases, including asthma, with significant racial and ethnic disparities.<sup>2,3</sup> The community experience is that health services and clinical researchers are good at measuring and documenting disparities, but this evidence may fail to translate into policy or practice that improves the health and quality of life of community residents in a timely way.

Recent trends in NIH funding of research seek to address many of these criticisms by calling for inclusion of more racial and ethnic minorities in health services and clinical research; requiring demonstration of the community's participation as partners in the research; placing greater emphasis on translation of research into policy and/or practice; and supporting more interdisciplinary approaches and interventions.

As Boston plans to keep and build on its leadership role in health and life sciences research, the response of academic medical researchers has been to turn to the urban underserved populations of the city. This article looks at partnerships between academic researchers and communities in urban Boston, outlining the experiences, identifying the challenges, and suggesting the solutions to avoid or resolve the conflicts inherent in these partnerships. The two case examples from which this article draws are excellent examples of the potential and complexity of these partnerships and have valuable lessons to be learned for community members and academic researchers finding themselves engaged in these growing efforts.

### **COMMUNITY-BASED PARTICIPATORY RESEARCH IN BOSTON'S NEIGHBORHOODS**

Community-based participatory research (CBPR) is a collaborative approach to research between academic researchers and communities that builds on the strengths and assets of the partners and engenders trust between them.<sup>4-7</sup> We recognize the many definitions of "community" employed in academic-community partnerships and concur that they are most often very much contextual and each project must have its own approach for defining its community of focus and determining how best to include them in their CBPR effort. We also recognize the varying levels of community involvement in research partnerships and follow the definition of CBPR contained in the Agency for Healthcare Research and Quality evidence report for the purposes of this article, accepting it as a model for improving research quality, enhancing community capacity and improving health outcomes.<sup>8</sup> CBPR is viewed as a preferred model when conducting research with vulnerable populations to reduce racial and ethnic disparities in health.<sup>9</sup>

The trends identified above and the increased interest in CBPR by government and foundation funders make organizations such as the Committee for Boston Public Housing, Inc. (CBPH) and the Center for Community Health Education Research and Service, Inc. (CCHERS) attractive community partners for academic researchers. CBPH is a multi-cultural organization of Boston public housing residents committed to social and economic justice for their families, their neighbors and themselves. Their mission is to build strong, safe and healthy public

housing communities through grassroots organizing, leadership development, and coalition building. CCHERS is a community-based partnership of Boston University School of Medicine, Northeastern University Bouvé College of Health Sciences, Boston Medical Center, the Boston Public Health Commission and a network of fifteen “academic community health centers” serving the diverse racial and ethnic populations of the city. The health centers’ legacy is in the struggle for health equity, access and social justice for disenfranchised populations and communities in the city of Boston. The two case studies detailed below involved collaborations between these organizations and academic partners.

### **CASE EXAMPLE #1—THE HEALTHY PUBLIC HOUSING INITIATIVE**

The Healthy Public Housing Initiative (HPHI) was a multi-year research and service project initiated in 2001, involving multiple authors of this article (DB, JIL, WMB-B, ER-C). HPHI had multiple aims, including: 1) improving home environments to improve health and increase quality of life for residents of public housing, including pediatric asthmatics; 2) building capacity within city agencies, community organizations, and resident groups to sustain the health focus beyond the project period; and 3) impacting state and national policy on multifamily housing design and health care financing for asthma. The focus on asthma and on pest management was motivated in large part by community concerns. The partners included the Boston Housing Authority, Boston Public Health Commission, Boston University School of Public Health, CBPH, Franklin Hill Tenant’s Task Force, Harvard School of Public Health, Peregrine Energy Group, Tufts University School of Medicine, Urban Habitat Initiatives, and West Broadway Tenant’s Task Force. Funding was initiated by the U.S. Department of Housing and Urban Development Healthy Homes Program, with additional funding from W.K. Kellogg Foundation, Ford Foundation, U.S. Environmental Protection Agency, The Boston Foundation and Jessie B. Cox Charitable Trust.

The project employed principles of CBPR partnerships, where not only were municipal agencies and grassroots community organizations full partners, but the project also recruited, trained and hired residents of public housing to collect field data and to participate in development of policy recommendations and, to a more limited extent, to participate in data analysis, interpretation and publication.

Three co-principal investigators, who were faculty at the three participating universities, led the project. This configuration was driven largely by previous pilot project experiences and by the financial management requirements imposed by a large and complex project (one institution administered the vast majority of the grants, issuing subcontracts to the other partners). The co-PIs chaired a steering committee that was comprised of representatives of all of the partner organizations. The steering committee met monthly and was often attended by residents, students, and multiple representatives of partner organizations. Meetings were generally informal and votes were taken only when particularly difficult issues arose that resulted in distinct differences among the partners. Larger project team meetings were also held monthly and were usually attended by a broader range of project staff. Due to the size of the initiative and numerous sub-projects, sub-committees were designated on a regular basis and most of the day-to-day work of the project emanated from these committees.

## **CASE EXAMPLE #2—ASTHMA CENTER ON COMMUNITY ENVIRONMENT AND SOCIAL STRESS (ACCESS)**

The Asthma Center on Community Environment and Social Stress (ACCESS) was a joint project funded in 2002 by the National Heart Lung and Blood Institute of the NIH as one of five national centers for research to reduce racial, ethnic and socio-economic disparities in asthma, involving multiple authors of this article (ERF and JIL). The funding mechanism was a cooperative agreement with NIH that created a partnership between a “research intensive institution” (RII) and a “minority serving institution” (MSI) through a single proposal but two separate applications and two separate grant awards, however funded as a partnership. The partners were the Channing Laboratory of Brigham and Women’s Hospital Harvard School of Public Health (Harvard) and CCHERS. The unique funding structure made the financial and organizational independence of the community partner in this instance a challenge for the academic partner. It leveled the playing field and tilted the usual power dynamics typical of these partnerships where the academic partner usually has most if not all of the power.

The project was designed to include a component of CBPR on the CCHERS arm to engage community health center patients, physicians and other providers in the research, both to address specific aims for the CCHERS arm of the project and to foster relationships that would facilitate recruitment for the Harvard arm of the project. Harvard focused on genetics, outdoor and indoor air quality, and elements of social stress and exposure to violence as potential risk factors for asthma development, with recruitment for a cohort study largely from community health centers. Each arm was led by a principal investigator, who along with the Executive Director of CCHERS, a biostatistician from Harvard School of Public Health, and the two project directors comprised an Executive Committee that met biweekly to oversee the implementation of the project while the larger project team met monthly.

The aims of this academic-community partnership were to (1) conduct comprehensive community assessments; (2) determine the role of social and physical environmental exposures; (3) determine the role of genetics in modifying the risk of the social/physical environment; and (4) evaluate the effectiveness of existing community health center asthma interventions. There were also training aims that involved both the community in understanding academic research and the academy in techniques of community engagement and a Community Advisory Board that would advise and support the work of ACCESS.

## **CHALLENGES WITHIN HPHI AND ACCESS**

While the challenges to successful partnerships for CBPR are many, some have been addressed and overcome in these two case examples, while others were harder to remedy. We highlight a few key challenges below.

### **Building Equitable Partnerships**

A significant challenge for any CBPR study, including ACCESS and HPHI, is to ensure that the academic-community collaboration is truly a partnership. The experience of the community partners is that they are often approached to participate in a research project after it has been conceived by an academic researcher, often in an area of their expertise and always driven by the grant requirements and guide-

lines of the funding agency. Even in studies like HPHI, which was informed to a significant extent by community interests, the community partners almost always find themselves advocating principles of partnership and CBPR at every table at which they sit, including: (1) the need for involving the community early at the conceptual stage of a project and maintaining a transparent process; (2) the value of hiring indigenous staff to collect and analyze data; (3) adequate support for building the capacity of the community partner to engage in the project; (4) designing and implementing an acceptable intervention and methodology; and (5) dissemination and utilization of findings.

A few additional factors can impede successful and equitable partnerships. One is related to financial resources from grants. Inequities in such resources or in the means to control and distribute those resources can create tensions, as occurred in the subcontracting structure of HPHI. In addition to simple issues of the relative magnitudes of resources, issues arose in HPHI regarding delays in subcontracts, which are relatively easy for academic institutions to tolerate but can cause significant financial burdens for community-based partners. University partners involved in CBPR should recognize this financial constraint and seek mechanisms to avoid delays in subcontract payments to community partners.

The somewhat unique funding structure for ACCESS was a way to address issues of power-sharing and equity in the distribution of resources, as well as other salient issues that arise in academic-community CBPR partnerships (i.e., joint identification of research priorities, joint ownership of research findings and recommendations, and building capacity in the community for engaging in research). While this alleviated some of the financial tensions, some fiscal issues remained, in part because the specific aims of Harvard depended on activities conducted by CCHERS, and vice versa. In addition, this funding structure imposed upon the MSI obligations more typical to a RII, including developing and implementing research protocols and addressing the concerns of five different Institutional Review Boards. There are pros and cons to this approach, as these responsibilities can help a community partner to develop important research skills, but if the funds and timing of the project do not afford the opportunity for capacity building, the project may not be successful.

A second challenge involves overcoming stereotypes. Academic researchers may have beliefs that community partners lack the infrastructure and capacity to be full partners in achieving the research aims of the project, which can immediately contribute to tensions and power differentials (in which academic researchers are uncomfortable ceding control over any aspects of the project). In HPHI, public housing residents were trained to work as community health advocates (CHAs) and to participate in data collection, either independently or alongside graduate students or field staff from the universities. There was tension throughout the project regarding the relative balance between relying on CHAs, which placed greater trust in the community partners and fulfilled a broader outreach and training mandate, and utilizing individuals with formal academic training. HPHI was ultimately able to utilize the skills of both CHAs and academic partners, with benefits that included personal successes for CHAs (i.e., job placement) and collection of data suitable for peer-reviewed publications. This CBPR approach required academic partners to shed (or at least limit) any stereotypes they may have harbored about public housing residents.

Just as academic researchers may harbor stereotypes about community partners, so may community partners have stereotypes about academic researchers. Commu-

nity groups may be cynical that the researchers are simply joining the collaboration to enhance their careers, gain access to subjects and data, and to write papers and retreat back to the ivory tower. These beliefs would lead to the stereotypes of academics as uncaring and lacking in any real connection to the problems of the community. In some cases, this cynicism may be justified, given previous experiences of the community with community-placed but not community-based research. However, it is not true that “if you have seen one academic, you have seen them all”; just as a single individual cannot be considered to represent an entire community, a single researcher cannot be considered to be representative of all researchers at their university. If the objectives of all participants are discussed upfront, and biases in both directions are opened up for discussion, it will enhance the likelihood of success. Mutual trust in each other’s skills and interests takes time to build and can be easily violated, so regular dialogue and transparency of the process is crucial. Even with regular meetings and collaborations that grew over multiple years, these issues of trust continued to be revisited in both HPHI and ACCESS throughout the project periods.

A third challenge is in reconciling the different cultures of the community-based organization and the academic institution and the way in which research is viewed and conducted. The traditional paradigm of the sole proprietary researcher as the principal investigator and therefore scientific leader does not allow for recognition of other forms of leadership that are just as critical to the success of community-based participatory research. CBPR, in its essence, needs to be more collaborative and builds on a team of co-investigators that bring varied expertise, strengths and assets to the process. The traditional model where the PI is the be all and end all does not promote the style of collegial team leadership necessary in CBPR efforts. In ACCESS, for example, when the CCHERS Director of Research and Evaluation (the “named” PI) resigned, it was viewed very negatively by the Harvard partners and NIH, as this represents a significant loss of skills and leadership in traditional scientific research enterprises. However, in this CBPR context, the CCHERS team capacity was not centered on this one individual, and the CCHERS side of the project could in fact have been strengthened by replacing the PI with someone with non traditional academic credentials but with stronger skills in applied research and evaluation and ties to the community.

### **Aligning Objectives and Expectations**

In any study, whether CBPR or otherwise, collaborators have differing objectives. Some may be focused on policy outcomes, while others are interested in building community infrastructure, writing peer-reviewed publications, or completing dissertations.<sup>10</sup> It is not realistic to expect all collaborators in a CBPR study to have identical objectives and attempting to impose that criterion will likely result in failure. Rather, attempts should be made early on to discuss each collaborator’s goals and objectives openly, with an attempt to reconcile any contradictory goals. For example, an academic partner may be engaged in a CBPR study partly to influence policy but may state that the work must also be publishable and that policy action should not occur in advance of peer review and publication. This may run counter to community needs for near-term action and for a study design that most benefits the community. If explicitly stated compromises can be reached the partnership should proceed. If not, perhaps this is not a good collaboration at this time.

One lesson that emerged from HPHI was that there was a tension between the research mission and the delivery of service to the affected community. In its early

development, HPHI partners were vague about whether the project was primarily about research or primarily about service. When the tension between research and service manifested itself, the project leadership generally dealt with conflicting interests by allowing partners to advocate for preserving the pieces they valued. This created a relatively democratic debate in the project but little explicit clarity, negotiation or deep agreement.

A key area of discussion early on was the design of the asthma intervention. The development of the intervention was complex and consisted of multiple stages. Initially, HPHI had a broad conception of the housing problems that it would address, including overall building infrastructure, with a plan to include a control group. This shifted to a series of interventions staggered in time and then to a single intervention focused on integrated pest management. While finances, time and sample size figured into the discussion, another issue raised by the community, the city and some of the researchers was that a scientifically sound and strong experimental design with a control group would deprive the control families of any benefits that came with the intervention, and to many this was unacceptable. In the end, the project adopted a longitudinal study with a single arm, but with dense data collection at many points in time.

But this too generated controversy, as some partners viewed the high cost of the data collection as excessive. This view arose from a concern that the large budget of the project had produced nominal services for public housing residents relative to the amount of money spent. In fact, this point of view was strongly held toward the end of the multi-year project, indicating that the concern was not one that had been resolved by earlier compromises in study design.

Interestingly, both the view that rigorous research was needed and the view that service provision should be primary led to substantial outcomes at the end of the project. Five of the original nine partners, largely centered on community and city partners, with the city as principal investigator, formed a collaboration that sought and received funding from the W.K. Kellogg Foundation to implement a community-driven integrated pest management program in Boston Public Housing that was based on the intervention used in the original HPHI study.

From the academic vantage point, in spite of the compromises in study design, numerous doctoral student dissertations were successfully completed using data from HPHI,<sup>11-14</sup> along with multiple publications to date.<sup>15-19</sup> One of the main health outcome papers wrestled with some of the implications of the modified study design, addressing the lack of a control group, the CBPR model, and the small sample size, all of which created a problem in disentangling a possible Hawthorn effect from the physical intervention.<sup>20</sup>

ACCESS provides another example of the complexity of balancing numerous objectives. Even among the academic partners, there were differences in goals and objectives, including the timing of various analyses and prioritization among different components of the cohort study. The academic-community collaboration proved challenging in this regard as well, given the simultaneous and sometimes conflicting objectives for capacity building and outreach at CCHERS and for recruiting and maintaining a large cohort at Harvard. As both sides of the ACCESS project attempted to build relationships with community health centers (for overlapping but sometimes differing purposes), both CCHERS and Harvard were confronted with the fact that the community health centers' buy-in to research is based on the belief that it is really going to make a difference in the lives of their patients and/or their community. As the public health providers in the city, they take

on responsibility for the community beyond their patients and their doors. As ACCESS was not an intervention study, this created challenges related to the differing definitions of “community” that the project aimed to serve (i.e., health center patients vs. the community at large vs. community health centers).

### LESSONS LEARNED AND NEXT STEPS

The brief discussion of HPHI and ACCESS above illustrates some of the challenges in CBPR, even when all partners have the best of intentions. The key is to develop approaches by which community participation in research can be enhanced and partnerships can be developed between researchers and communities. We found that open and honest two-way communication is essential, but that perfect agreement is not. Even when objectives and perceptions differ among partners (as they always will), it is important to articulate this upfront and deal with the consequences.

Although both HPHI and ACCESS had their share of conflicts, we would argue that this is a sign of a healthy collaboration (since the alternative is for the inevitable problems to go unstated). Related to this point, CBPR studies need to pay attention to the details of the project, since seemingly minor aspects of complex collaborations can cause intractable problems and contribute to mistrust. In any CBPR effort, time needs to be devoted to process and relationship-building, long in advance of a grant deadline or project start date—the process itself may be as important as the product. Relationships that are initiated to respond to a specific grant opportunity have likely not gone through this process prior to the start of the project. While there are numerous mechanisms by which this relationship building can occur, there is no “one size fits all” approach that will work for the diverse set of activities that can be called CBPR.

As a final observation, none of the above challenges should be viewed as indictments or limitations of CBPR itself—the same sets of rules could be applied to collaborations among academics. Nevertheless, if CBPR projects are able to move past issues such as mutual stereotypes and misaligned objectives, they will be more likely to be beneficial to all partners and the community at large.

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