



# Challenges in Improving Community Engagement in Research

## Chapter 5

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### INTRODUCTION

This chapter addresses common challenges faced in community-engaged research, whether that research meets the definition of community-based participatory research (CBPR) or falls elsewhere on the spectrum of community engagement efforts. These challenges and some approaches for meeting them are illustrated with a series of vignettes that describe real-life experiences of partnerships emanating from the Prevention Research Centers (PRC) program, the Clinical and Translational Science Awards (CTSA) program, and other community-engaged research (CEnR) efforts.

CDC funds PRCs in schools of public health and medicine; the first three PRCs were funded in 1986. Currently, 37 PRCs are funded across 27 states, working as an interdependent network of community, academic, and public health partners to conduct applied prevention research and support the wide use of practices proven to promote good health. These partners design, test, and disseminate strategies that can be implemented as new policies or

recommended public health practices. For more information on the PRC program, visit [www.cdc.gov/prc](http://www.cdc.gov/prc).

The CTSA program began in 2006 with 12 sites funded by the National Center for Research Resources, a part of NIH. As of publication, the CTSA Consortium includes 55 medical research institutions located throughout the nation that work together to energize the discipline of clinical and translational science. The CTSA institutions share a common vision to improve human health by transforming the research and training environment in the U.S. to enhance the efficiency and quality of clinical and translational research. Community engagement programs in the CTSA help foster collaborative and interdisciplinary research partnerships, enhance public trust in clinical and translational research, and facilitate the recruitment and retention of research participants to learn more about health issues in the United States' many diverse populations. For more information on the CTSA Consortium, visit [www.CTSAweb.org](http://www.CTSAweb.org).

The purpose of this chapter is to address five key challenges in the area of community-engaged research:

1. Engaging and maintaining community involvement.
2. Overcoming differences between and among academics and the community.
3. Working with nontraditional communities.
4. Initiating a project with a community and developing a community advisory board.
5. Overcoming competing priorities and institutional differences.

Each vignette describes a challenge faced by a partnership and the actions taken and provides pertinent take-home messages. The intention is to provide readers with snapshots of community engagement activity during the research process. Readers are encouraged to contact the authors or refer to the references for further information concerning findings and follow-up.

## 1. ENGAGING AND MAINTAINING COMMUNITY INVOLVEMENT

Many communities distrust the motives and techniques of research. Some know of the history of exploitation and abuse in medical research in the U.S., and others may be “burned out” from participation in studies. Some may have immediate needs that make research seem irrelevant, and some may merely lack an understanding of the research enterprise.

Thus, when research is involved, the challenges of community engagement may be particularly profound. The vignettes that follow address some of the most common dilemmas in engaging a community in research and maintaining the relationship over time. The take-home messages offered at the end of each vignette are grounded in the principles of community engagement, as they demonstrate the importance of understanding communities; establishing trusting, respectful, equitable, and committed relationships; and working with the community to identify the best ways to translate knowledge into improved health.

### *A. How do you engage a community in a randomized clinical trial or a drug trial?*

*Sally Davis, PhD*

#### **Challenge**

Community-based research does not always allow for full participation of the community from start to finish, as is envisioned in the classic CBPR model. In CBPR, the community often comes up with the research question or issue of interest based on personal experience, but in a randomized controlled trial (RCT), the funding agency or investigator generally develops the question based on pressing health issues identified from surveillance or other data sources. A community-based RCT is often an efficacy trial and may include many schools or communities across a large geographic area.

For example, the PRC at the University of New Mexico conducted an RCT on obesity prevention with 16 rural Head Start centers across the state. An RCT conducted in the traditional way is done in an artificial “laboratory” setting within an academic health center or practice setting; an RCT in the

community setting can be just as rigorous but with more flexibility and community participation. The challenge has been to develop strategies to engage the community in the research process within a short period of time and with clear communication and agreement.

### **Action Steps**

Although the study was conducted in 16 communities and there was little time to establish relationships, researchers were able to engage the communities by inviting key partners to participate. For example, local grocery stores, health care providers, families, Head Start teachers, teaching assistants, and food-service providers were all included. This inclusive approach ensured participation from a broad array of community members from the

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beginning of the study. A memorandum of agreement (MOA) was developed that included input from community leaders and provided an opportunity for the researchers and the community to discuss and agree on roles, responsibilities, and expectations. Key members of the community (e.g., governing officials, school administration, and parent groups) and the university researchers signed the agreement. The MOA includes a clear statement of the purpose of the research, burden to the school or individual (the amount of time required to participate), benefits to the school (money, equipment, in-kind service), benefits to the academic institution and researchers (the opportunity to answer important questions and test interventions), needs (space, parental consent, special events, identification of other key individuals), and communication issues (regarding scheduling, staff turnover, complaints). The MOA is being used as a guidance document for the study. Having this agreement in writing is especially helpful when there is turnover of key participants, such as school staff or governing officials, or when there are new participants who may not be aware of the history or purpose of the study or of the roles, relationships, and responsibilities agreed upon at the beginning of the research.

### **Take-Home Messages**

- Engaging the community in RCTs is challenging but possible.
- Engaging and seeking input from multiple key stakeholders (e.g., grocery store owners, health care providers, and families) is an important strategy.

- Collaboratively developing an MOA can enhance communication and build new partnerships in studies that are restricted by time and are predefined.
- An MOA can serve as a valuable guidance document and useful tool throughout a study as an agreed-upon point of reference for researchers and community members (Davis et al., 1999; Davis et al., 2003).

## References

Davis SM, Clay T, Smyth M, Gittelsohn J, Arviso V, Flint-Wagner H, et al. Pathways curriculum and family interventions to promote healthful eating and physical activity in American Indian schoolchildren. *Preventive Medicine* 2003;37(6 Part 2):S24-34.

Davis SM, Going SB, Helitzer DL, Teufel NI, Snyder P, Gittelsohn J, et al. Pathways: a culturally appropriate obesity-prevention program for American Indian schoolchildren. *American Journal of Clinical Nutrition* 1999;69(4 Suppl):796S-802S.

### *B. How do you overcome historical exploitation?*

*Sally Davis, PhD, Janet Page-Reeves, PhD, Theresa Cruz, PhD*

## Challenge

A history of exploitation in rural communities may be manifested in a number of ways. In many such communities, structural inequality is evident in residents' geographic isolation, great distance from commercial centers, lack of access to services, lack of availability of healthful foods, and poverty, as well as frequent turnover of staff in local institutions such as schools and health care facilities. This reality presents everyday challenges to the researchers at institutions that work in these communities. For example, distance, weather, and lack of infrastructure pose logistical challenges, and a lack of road maintenance, limited communication capacity, and uncertain access to food and lodging (necessities that urban residents may take for granted) are often problems in rural areas. These issues, combined with the problem of scheduling around competing priorities in the lives of both researchers and community members, are challenges for those living in or working with rural communities.

These challenges do not compare, however, with those created by the historical exploitation of residents in some of these communities. In the Southwest, where research has too often been conducted in an exploitative manner without the consent and participation of the community, it is extremely difficult to develop partnerships between rural communities and researchers. Many American Indian and Hispanic communities throughout the Southwest have been the subjects of research conducted by persons living outside the community who did not engage residents and their communities in the research. In one multisite study with tribal groups across the United States that began in the 1990s, researchers at the University of New Mexico PRC and at four other universities were confronted with the challenge of overcoming the mistrust of seven tribal communities that had either experienced exploitation or heard of examples.

### **Action Steps**

Despite the history of violated trust, the PRC was able to develop appropriate and meaningful partnerships between researchers and tribal communities. Together, the partners established and maintained the bidirectional trust necessary to develop and implement a successful intervention. They used a variety of participation strategies to achieve trust. For example, local customs and cultural constructs were considered in formulating the intervention, local advisory councils were formed, elders were included as advisors, local community members were hired, formative assessment was conducted to determine the feasibility and acceptability of the proposed prevention strategies in local terms, approval was sought from tribal and local review boards, and local priorities were determined. Participation, feedback, and collaborative relationships were crucial to engaging these underrepresented communities with a history of exploitation. And yet, perhaps the most important and most basic strategy was to demonstrate respect and inclusion to the fullest extent possible.

Together, the partners established and maintained the bidirectional trust necessary to develop and implement a successful intervention.

### **Take-Home Messages**

- Recognize that there may be a history of exploitation in the community and therefore a distrust of research and researchers.

- Employ a variety of participation strategies.
- Allow extra time for building relationships and trust.
- Seek approval from tribal or other local review groups.
- Include local customs in interventions.
- Demonstrate respect and inclusion to the fullest extent possible (Davis et al., 1999; Gittelsohn et al., 2003).

## References

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Gittelsohn J, Davis SM, Steckler A, Ethelbah B, Clay T, Metcalfe L, et al. Pathways: lessons learned and future directions for school-based interventions among American Indians. *Preventive Medicine* 2003;37(6):S107-S112.

### *C. How do you maintain community engagement throughout the research?*

*Deborah Bowen, PhD*

## Challenge

The comedian Woody Allen once said, “Eighty percent of life is showing up.” That is true in community engagement as well as in life. Add to that formula the idea of showing up for the right events — those that are important to community priorities — and engagement takes place. For example, the author’s research group was funded to conduct a feasibility study of using rural farm granges as health promotion sites in ranching country. Granges are rural community organizations that support learning, information exchange, social events, and political action for farming and ranching communities. The feasibility study progressed from initial discussions to collection of formative data. These data collection efforts were by telephone, and, at first, response rates from the actual membership were relatively poor. The research group



halted its efforts to collect data and conducted some qualitative research to better understand the issues.

### **Action Steps**

The researchers found that lack of familiarity with the author's research institute and the people involved might be one barrier to full participation of the rural residents and grange members.

The researchers found that lack of familiarity with the author's research institute and the people involved might be one barrier to full participation of the rural residents and grange members. Over the next six months, the research institute staff began to attend community and farming events, getting to know residents and families and learning what the community's important issues were. Research institute staff asked about these issues and attended events or supported efforts in the farming communities that were not necessarily related to health promotion but were key to the farm families in the granges. Several farm family members became part of the project's community advisory board, giving both advice and direction to the new plans for surveys. After six months, the research group, together with the community advisory board, reinstated the telephone data collection efforts, which then achieved a much higher response rate. This kind of community engagement continued for the three-year project. These same connections with farm families in granges are still fueling health promotion efforts in this area.

### **Take-Home Messages**

- Engagement needs to occur as the ideas for research are being formed and the procedures are being identified.
- Taking the community's priorities into account increases the opportunity for engagement.
- Being a regular presence in the community may enhance research efforts.

### ***D. How do you engage a community organization as a partner in exploratory health research?***

*Lori Carter-Edwards, PhD, Ashley Johnson, Lesley Williams, Janelle Armstrong-Brown, MPH*

## **Challenge**

The John Avery Boys and Girls Club (JABGC), located in the heart of a low-to-lower-middle-income community in Durham, North Carolina, primarily serves African American children and their families by providing a variety of after-school programs and activities. The organization is partnering with the Duke Center for Community Research (DCCR) to conduct a qualitative exploratory research study to understand children's influences on the food purchasing behaviors of caregivers in the context of food marketing. African American children have a much higher prevalence of obesity than children of other ethnic groups (Skelton et al., 2009) and are more likely than other children to receive targeted marketing messages for products associated with intake of excess calories (Grier et al., 2010; Kumanyika et al., 2006). The intent of this study is to gain information on the local food environment to help inform and ultimately to modify policy. JABGC had a previous relationship with DCCR personnel in the area of program and policy development, but this was its first experience serving as a full partner with the DCCR in research.

## **Action Steps**

The DCCR and the JABGC have met regularly since the development and funding of the study, which is sponsored by the African-American Collaborative Obesity Research Network, a national research network based at the University of Pennsylvania through a grant from the Robert Wood Johnson Foundation. The executive director of the JABGC identified an administrative lead from the club to serve as its point person. The DCCR faculty lead for the study and other researchers frequently visit the JABGC and have established a rapport with its entire administrative and programmatic staff. The core partners hold weekly telephone meetings to address issues related to execution of the study. During some calls, partners have discussed the data that needed to be collected and why, and these discussions helped to dramatically improve documentation. Regular telephone meetings also helped to clarify job priorities. It was important that the DCCR partners understood the work priorities of the JABGC staff and the limitations of what could and could not be accomplished during the study.

Some of the JABGC administrative staff has changed since the research began, but because of the rapport built through the partnership and the existing

mechanisms for communication, the changes have not adversely affected the team's ability to conduct the research. Continued communications between the DCCR and the JABGC administrative and programmatic staff have been key to sustaining organizational relationships.

### **Take-Home Messages**

- Establishing a collaborative research relationship may involve a different level of engagement than a collaborative outreach relationship.
- Organizations have their own responsibilities that have to be met independently of any research.
- Communicating regularly and often to keep all partners aware of priorities within the respective institutions is important.
- Working collectively to proactively create relationships and put procedures in place can help sustain the research when the community organization staff changes.
- It should be understood that, despite the time limits for research, partnerships must be flexible.

### **References**

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Kumanyika S, Grier S. Targeting interventions for ethnic minority and low-income populations. *The Future of Children* 2006;16(1):187-207.

Skelton JA, Cook SR, Auinger P, Klein JD, Barlow SE. Prevalence and trends of severe obesity among US children and adolescents. *Academic Pediatrics* 2009;9(5):322-329.

## 2. OVERCOMING DIFFERENCES BETWEEN AND AMONG ACADEMICS AND THE COMMUNITY

The backgrounds and languages of researchers are often different from those of community members. The concept of culture noted in Chapter 1 captures the different norms that can govern the attitudes and behaviors of researchers and those who are not part of the research enterprise. In addition, the inequalities highlighted by the socio-ecological perspective often manifest in difficult “town-gown” relationships. How can these differences be overcome in the interests of CEnR?

### *A. How do you engage the community when there are cultural differences (race or ethnicity) between the community and the researchers?*

*Kimberly Horn, EdD, Geri Dino, PhD*

#### **Challenge**

American Indian youth are one of the demographic groups at highest risk for smoking (Johnston et al., 2002; CDC, 2006), and yet there is little research regarding effective interventions for American Indian teens to prevent or quit smoking. Unfortunately, American Indians have a long history of negative experiences with research, ranging from being exploited by this research to being ignored by researchers. Specifically, they have been minimally involved in research on tobacco addiction and cessation in their own communities. This problem is compounded by the economic, spiritual, and cultural significance of tobacco in American Indian culture. In the late 1990s, the West Virginia University PRC and its partners were conducting research on teen smoking cessation in North Carolina, largely among white teens. Members of the North Carolina American Indian community approached the researchers about addressing smoking among American Indian teens, focusing on state-recognized tribes.

#### **Action Steps**

CBPR approaches can be particularly useful when working with underserved communities, such as American Indians, who have historically been exploited. For this reason, CBPR approaches served as the framework for

The researchers and the community board developed a document of shared values to guide the research process.

a partnership that included the West Virginia University PRC, the North Carolina Commission of Indian Affairs, the eight state-recognized tribes, and the University of North Carolina PRC. The CBPR-driven process began with formation of a multi-tribe community partnership board composed of tribal leaders, parents, teachers, school personnel, and clergy. The researchers and the community board developed a document of shared values to guide the research process. Community input regarding the nature of the program was obtained from focus groups, interviews, surveys, and informal discussions, including testimonials and numerous venues for historical storytelling.

As the community and the researchers continued to meet, they encountered challenges concerning the role and meaning of tobacco in American Indian culture. The researchers saw tobacco as the problem, but many community members did not share that view. This was a significant issue to resolve before the project could move forward. A major breakthrough occurred when the partners reached a declarative insight that *tobacco addiction*, not tobacco, was the challenge to be addressed. From that day forward, the group agreed to develop a program on smoking cessation for teens that specifically addressed tobacco addiction from a cultural perspective. In addition, the community decided to use the evidence-based Not on Tobacco (N-O-T) program developed by the West Virginia University PRC as the starting point. American Indian smokers and nonsmokers, N-O-T facilitators from North Carolina, and the community board all provided input into the program's development. In addition, teen smokers provided session-by-session feedback on the original N-O-T program. Numerous recommendations for tailoring and modifying N-O-T resulted in a new N-O-T curriculum for American Indians. The adaptation now provides 10 tailored sessions (Horn et al., 2005a; Horn et al., 2008).

The N-O-T program as modified for American Indians continues to be used in North Carolina, and there are ongoing requests from various tribes across the U.S. for information about the program. The initial partnership was supported by goodwill and good faith, and the partnership between American Indians and N-O-T led to additional collaborations, including a three-year CDC-funded CBPR project to further test the American Indian N-O-T program and to alter the political and cultural norms related to tobacco across North Carolina tribes. Critically, grant resources were divided almost equally among

the West Virginia PRC, the North Carolina PRC, and the North Carolina Commission on Indian Affairs. Each organization had monetary control over its resources. In addition, all grants included monies to be distributed to community members and tribes for their participation. This statewide initiative served as a springboard for localized planning and action for tobacco control and prevention across North Carolina tribes (Horn et al., 2005b).

### **Take-Home Messages**

- Act on the basis of value-driven, community-based principles, which assure recognition of a community-driven need.
- Build on the strengths and assets of the community of interest.
- Nurture partnerships in all project phases; partnership is iterative.
- Integrate the cultural knowledge of the community.
- Produce mutually beneficial tools and products.
- Build capacity through co-learning and empowerment.
- Share all findings and knowledge with all partners.

### **References**

Centers for Disease Control and Prevention. Cigarette smoking among adults—United States, 2006. *Morbidity and Mortality Weekly Report* 2007;56(44):1157-1161.

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Horn K, McCracken L, Dino G, Brayboy M. Applying community-based participatory research principles to the development of a smoking-cessation program for American Indian teens: “telling our story.” *Health Education and Behavior* 2008;35(1):44-69.

Horn K, McGloin T, Dino G, Manzo K, McCracken L, Shorty L, et al. Quit and reduction rates for a pilot study of the American Indian Not On Tobacco (N-O-T) program. *Preventing Chronic Disease* 2005b;2(4):A13.

Johnston L, O'Malley P, Bachman J. *Monitoring the future national survey results on drug use, 1975–2002*. NIH Publication No.03-5375. Bethesda (MD): National Institute on Drug Abuse; 2002.

*B. How do you work with a community when there are educational or sociodemographic differences between the community and the researchers?*

*Marc A. Zimmerman, PhD, E. Hill De Loney, MA*

### **Challenge**

University and community partners often have different social, historical, and economic backgrounds, which can create tension, miscommunication, and misunderstanding. These issues were evident in a recent submission of a grant proposal; all of the university partners had advanced degrees, came from European-American backgrounds, and grew up with economic security. In contrast, the backgrounds of the community partners ranged from two years of college to nearing completion of a Ph.D., and socioeconomic backgrounds were varied. All of the community partners were involved in a community-based organization and came from African American backgrounds.

Despite extensive discussion and a participatory process (e.g., data-driven dialogue and consensus about the final topic selected), the community-university partnership was strained during the writing of the proposal. Time was short, and the university partners volunteered to outline the contents of the proposal, identify responsibilities for writing different parts of the proposal, and begin writing. The proposal details (e.g., design, contents of the intervention, recruitment strategy, and comparison community) were discussed mostly through conference calls.

## Action Steps

The university partners began writing, collating what others wrote, and initiating discussions of (and pushing for) specific design elements. Recruitment strategy became a point of contention and led to heavy discussion. The university partners argued that a more scientifically sound approach would be to recruit individuals from clinic settings that had no prior connections to those individuals. The community partners argued that a more practical and locally sound approach would be to recruit through their personal networks. No resolution came during the telephone calls, and so the university partners discussed among themselves the two sides of the argument and decided to write the first draft with participants recruited from clinic settings (in accord with their original position). The university partners sent the draft to the entire group, including the county health department and a local health coalition as well as the community partners, for comments.

The community partners did not respond to drafts of the proposal as quickly as the university partners expected, given the deadlines and administrative work that were required to get the proposal submitted through the university. This lack of response was interpreted by the university partners as tacit approval, especially given the tight deadline. However, the silence of the community partners turned out to be far from an expression of approval. Their impression, based on the fact that the plan was already written and time was getting shorter, was that the university partners did not really want feedback. They also felt that they were not respected because their ideas were not included in the proposal. The university partners, however, sincerely meant their document as a draft and wanted the community partners' feedback about the design. They thought there was still time to change some aspects of the proposal before its final approval and submission by the partnership. The tight deadline, the scientific convictions of the university partners, the reliance on telephone communications, and the imbalance of power between the partners all contributed to the misunderstanding and miscommunication about the design. This process created significant problems that have taken time to address and to heal.



## Take-Home Messages

- Be explicit that drafts mean that changes can be made and that feedback is both expected and desired.
- Have more face-to-face meetings, especially when discussing points about which there may be disagreement, because telephone conferencing does not allow for nonverbal cues and makes it more difficult to disagree.
- Figure out ways to be scientifically sound in locally appropriate ways.
- Acknowledge and discuss power imbalances.
- Ensure that all partners' voices are heard and listened to, create settings for open and honest discussion, and communicate perspectives clearly.
- Help partners understand when they are being disrespectful or might be misinterpreted.
- Discuss differences even after a proposal is submitted.
- Improve communication by establishing agreed-upon deadlines and midpoint check-ins, using active listening strategies, specifically requesting feedback with time frames, and facing issues directly so that everyone understands them.
- Provide community partners with time and opportunity for developing designs for proposals, and provide training for community partners if they lack knowledge in some areas of research design.
- Set aside time for university partners to learn about the community partners' knowledge of the community and what expertise they bring to a specific project.
- Acknowledge expertise within the partnership explicitly and take advantage of it when necessary.

*C. How do you engage a community when there are cultural, educational, or socioeconomic differences within the community as well as between the community and the researchers?*

*Seronda A. Robinson, PhD, Wanda A. Boone, RN, Sherman A. James, PhD, Mina Silberberg, PhD, Glenda Small, MBA*

## **Challenge**

Conducting community-engaged research requires overcoming various hierarchies to achieve a common goal. Hierarchies may be created by differing economic status, social affiliation, education, or position in the workplace or the community. A Pew Research Center survey, described by Kohut et al. (2007), suggests that the values of poor and middle-class African Americans have moved farther apart from each other in recent years and that middle-class African Americans' values have become more like those of whites than of poor African Americans. In addition, African Americans are reporting seeing greater differences created by class than by race (Kohut et al. 2007). It is widely known that perceived differences in values may influence interactions between groups.

Approaches to engage the community can be used as bridge builders when working with economically divided groups. The African-American Health Improvement Partnership (AAHIP) was launched in October 2005 in Durham, North Carolina, with a grant from the National Center (now Institute) for Minority Health and Health Disparities through a grant program focused on community participation. The AAHIP research team consists of African American and white researchers from Duke University with terminal degrees and research experience and health professionals/community advocates from the Community Health Coalition, Inc, a local nonprofit. The community advisory board (CAB) is composed of mostly African American community leaders representing diverse sectors of Durham's African American and health provider communities. The first study launched by the AAHIP, which is ongoing, is an intervention designed by the AAHIP CAB and its research team to improve disease management in African American adults with type 2 diabetes.

*Approaches to engage the community can be used as bridge builders when working with economically divided groups.*

At meetings of the CAB, decisions were to be made by a majority vote of a quorum of its members. Members of the research team would serve as facilitators who provided guidance and voiced suggestions. The sharing of information was understood to be key to the process. However, dissimilarities in educational level and experience between the research team and the CAB and variations in socioeconomic status, positions, and community roles among CAB members created underlying hierarchies within the group (i.e., the CAB plus the research team). The research team assumed a leadership role in making recommendations. Notably, even within the CAB, differences among its members led to varying levels of comfort with the CAB process with the result that some members did most of the talking while others were hesitant to make contributions. Many of the community leaders were widely known for their positions within the community and their accomplishments, and these individuals were accustomed to voicing their opinions, being heard, and then being followed. Less influential members were not as assertive.

### **Action Steps**

Faculty from North Carolina Central University, a historically black university in Durham, conduct annual evaluations to assess the functioning of the CAB and the research team, in particular to ensure that it is performing effectively and meeting the principles of CBPR. An early survey found that only about 10% of respondents felt that racial differences interfered with productivity, and 19% felt that the research team dominated the meetings. However, nearly half felt that the meetings were dominated by just one or a few members. Although more than 90% reported feeling comfortable expressing their point of view at the meetings, it was suggested that there was a need to get everyone involved.

CAB members suggested ways to rectify the issues of perceived dominance, and all parties agreed to the suggestions. From then on, the entire CAB membership was asked to contribute to the CAB meeting agendas as a way to offer a larger sense of inclusion. At the meetings themselves, the chair made a point of soliciting remarks from all CAB members until they became more comfortable speaking up without being prompted. In addition, subcommittees were established to address important business. These made active participation easier because of the size of the group.

As seats came open on the CAB, members were recruited with an eye to balancing representation in the group by various characteristics, including gender, age, socioeconomic status, and experience with diabetes (the outcome of interest). Overall, a change was seen in the level of participation at meetings, with more members participating and less dominance by a few. Moreover, former participants in the type 2 diabetes intervention were invited to join the CAB and have now assumed leadership roles.

### **Take-Home Messages**

- Evaluate your process on an ongoing basis and discuss results as a group.
- Assure recognition of a community-driven need through strong and fair leadership.
- Make concerted efforts to draw out and acknowledge the voices of all participants.
- Create specialized committees.
- Engage participants in the choosing of new board members (especially former participants).

### **Reference**

Kohut A, Taylor P, Keeter S. Optimism about black progress declines: blacks see growing values gap between poor and middle class. *Pew Social Trends Report* 2007;91. Retrieved from <http://pewsocialtrends.org/files/2010/10/Race-2007.pdf>.

### 3. WORKING WITH NONTRADITIONAL COMMUNITIES

As described in Chapter 1, communities vary greatly in their composition. New communication technologies mean that increasingly there are communities that do not conform to geographic boundaries and that collaboration can occur across great distances. These new kinds of communities and collaborations have their own unique challenges, illustrated in the following vignettes.

#### *A. How do you maintain community engagement when the community is geographically distant from the researchers?*

*Deborah Bowen, PhD*

#### **Challenge**

Distance poses a sometimes insurmountable barrier to open and accurate communication and engagement. People may feel left out if they perceive that distance is interfering with the connections between the research team and partners in the community. Maintaining involvement in multiple ways can solve this problem.

The principal investigator (PI) of an NIH-funded project was located at an academic institution, whereas community partners (Alaskan Natives and American Indians) were scattered through 40 sites across a large region in the U.S. Before the project began, the PI knew that even with an initial positive response, participation in the project would be hard to maintain across a multiyear project. She used two strategies to maintain contact and connection with the 40 community partners: refinements in organization and strategic personal visits.

#### **Action Steps**

The PI identified each community organization's preferred method for communication and used that method for regular scheduled contacts. The methods were mostly electronic (telephone, email, or fax). Every scheduled contact

brought a communication from the contact person in the community, no matter how insignificant. The community partners contributed to the communication, and if they had an issue they communicated it to the contact person. The communications were used to solve all kinds of problems, not just those that were research related. In fact, communications were social and became sources of support as well as sources of project information. This contact with the 40 community partners was continued for the duration of the six-year project.

The PI knew that relying on electronic communication alone was not sufficient. Thus, despite the vast distances between her institution and the community partners, the PI scheduled at least annual visits to see them. She asked each partner for the most important meeting or event of the year and tried to time the visit to attend it. The face-to-face interaction allowed by these visits was meaningful to the PI and the partners. The PI followed the cultural rules of visits (e.g., bringing gifts from their region to the community partners). Even with the barriers of space and time, engagement at a personal level made the research activities easier and more memorable for the partners.

The face-to-face interaction allowed by these visits was meaningful to the PI and the partners.

### **Take-Home Messages**

- Take communication seriously, even if it is inconvenient to do so.
- Keep notes or files on the people involved to remember key events.
- Take into consideration the community partner's perspective on what is important.

### **Reference**

Hill TG, Briant KJ, Bowen D, Boerner V, Vu T, Lopez K, Vinson E. Evaluation of Cancer 101: an educational program for native settings. *Journal of Cancer Education* 2010;25(3):329-336.

## *B. How do you engage a state as a community?*

*Geri Dino, PhD, Elizabeth Prendergast, MS, Valerie Frey-McClung, MS, Bruce Adkins, PA, Kimberly Horn, EdD*

### **Challenge**

West Virginia is the second most rural state in the U.S. with a population density of just 75 persons per square mile. The state consistently has one of the worst health profiles in the nation, including a disproportionately high burden of risk factors for chronic disease. The most notable is tobacco use (Trust for America's Health, 2008). Addressing these chronic disease risk disparities was central to West Virginia University's application to become a CDC-funded PRC. Early in the application process, senior leadership from the university engaged the state's public health and education partners to create a vision for the PRC. Both then and now, the PRC's state and community partners view West Virginia as having a culture of cooperation and service that embraces the opportunity to solve problems collectively. The vision that emerged, which continues to this day, reflected both the state's need and a sense of shared purpose — the entire state of West Virginia would serve as the Center's target community. Importantly, the academic-state partners committed themselves to develop the PRC as the state leader in prevention research by transforming public health policy and practice through collaborative research and evaluation. In addition, partners identified tobacco use as the top research priority for the PRC. These decisions became pivotal for the newly established Center and began a 15-year history of academic-state partnerships in tobacco control.

### **Action Steps**

Several critical actions were taken. First, in 1995, West Virginia had the highest rate of teen smoking in the nation, and thus the academic-state partners determined that smoking cessation among teens would be the focus of the Center's core research project. Second, faculty were hired to work specifically on state-driven initiatives in tobacco research. Third, PRC funds were set aside to conduct tobacco-related pilot research using community-based participatory approaches. Fourth, state partners invited Center faculty to tobacco control meetings; the faculty were encouraged to provide guidance

and research leadership. Partners also committed to ongoing collaborations through frequent conference calls, the sharing of resources, and using research to improve tobacco control policy and practice. In addition, a statewide focus for the PRC was reiterated. In 2001, the PRC formed and funded a statewide Community Partnership Board to ensure adequate representation and voice from across the state. This board provided input into the PRC's tobacco research agenda. Partners collectively framed pilot research on tobacco and the original core research project, the development and evaluation of the N-O-T teen smoking cessation program.

Partners also committed to ongoing collaborations through frequent conference calls, the sharing of resources, and using research to improve tobacco control policy and practice.

Significantly, the Bureau for Public Health, the Department of Education Office of Healthy Schools, and the PRC combined their resources to develop and evaluate N-O-T. Soon after, the American Lung Association (ALA) learned about N-O-T and was added as a partner. The ALA adopted N-O-T, and the program is now a federally designated model program with more than 10 years of research behind it. It is also the most widely used teen smoking cessation program in both the state and the nation (Dino et al., 2008). The Bureau's Division of Tobacco Prevention continues to provide resources to disseminate N-O-T statewide. The PRC, in turn, commits core funds to the Division's partnership activities.

Additionally, the PRC and the Office of Healthy Schools collaborated to assess West Virginia's use of the 1994 CDC-recommended guidelines on tobacco control policy and practice in schools. Partners codeveloped a statewide principals' survey and used survey data to create a new statewide school tobacco policy consistent with CDC guidelines (Tompkins et al., 1999). Within a year, the West Virginia Board of Education Tobacco-Free Schools Policy was established by Legislative Rule §126CSR66. As collaborations grew, the state received funds from the 2001 Master Settlement Agreement; some of these funds were used by the Division of Tobacco Prevention to establish an evaluation unit within the PRC. This unit became the evaluator for tobacco control projects funded through the Master Settlement as well as by other sources. The evaluation unit has been instrumental in helping the programs improve their process of awarding grants by helping to develop a request for proposals (RFP) and by providing training in grant writing and evaluation



to those applying for funds. The evaluators continue to develop tools and reporting guidelines to measure success. Through the years, this process has allowed the Division of Tobacco Prevention to identify the organizations best suited to carry out tobacco control efforts, and two highly successful, regional tobacco-focused networks have been created — one community based and the other school based. The Division, which consistently makes programmatic decisions based on evaluation reports and recommendations from the PRC, believes that the PRC-state collaboration has been one of the key partnerships leading to the many successes of the tobacco prevention and control program. In the words of Bruce Adkins, Director of the Division of Tobacco Prevention, the state-PRC evaluation partnerships:

ensure that our tobacco prevention and cessation efforts are founded in science, responsive to communities, and accountable to state policy-makers. Based on PRC guidance and CDC Best Practices collaboration, we only fund evidence-based programs, and we continuously quantify and qualify every intervention we fund. Without the PRC, our division would have far fewer successes to share with the nation. (personal communication with Mr. Adkins, September 2008)

### **Take-Home Messages**

- There must be an ongoing commitment to the partnership, and it must be reinforced on a continuing basis.
- Partners need to establish a set of shared values, such as recognizing the importance of a statewide focus, using CBPR approaches, and emphasizing the importance of research translation.
- Partners must commit to shared decision making and shared resources.
- Roles and responsibilities should be defined based on complementary skill sets.
- Partners must establish mutual respect and trust.

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## 4. INITIATING A PROJECT WITH A COMMUNITY AND DEVELOPING A COMMUNITY ADVISORY BOARD

As described in Chapter 1, partnerships evolve over time. Often, the first steps toward engagement are the most difficult to take. The vignettes in this section demonstrate some effective ways of initiating research collaborations.

### *A. How do you start working with a community?*

*Daniel S. Blumenthal, MD, MPH*

#### **Challenge**

In the mid-1980s, the Morehouse School of Medicine in Atlanta was a new institution, having been founded only a few years earlier. Because its mission called for service to underserved communities, two contiguous low-income African American neighborhoods in southeast Atlanta were engaged. These neighborhoods, Joyland and Highpoint, had a combined population of about 5,000 and no established community organization. Morehouse dispatched a community organizer to the area, and he spent the next few months learning about the community. He met the community leaders, ministers, businesspeople, school principals, and agency heads, and he secured credibility by supporting neighborhood events and even buying t-shirts for a kids' softball team. Soon, he was able to bring together the leaders, who now knew and trusted him (and, by extension, Morehouse), to create and incorporate the Joyland-Highpoint Community Coalition (JHCC).

With the help of the community organizer, the JHCC conducted an assessment of the community's health needs, mostly by surveying people where they gathered and worked. Drug abuse was at the top of the community's problem list, and Morehouse secured a grant to conduct a project on preventing substance abuse. Most of the grant was subcontracted to the JHCC, which was able to use the funds to hire a project director (who also served as the organization's executive director) and other staff.

## Action Steps

Morehouse continued to work with Joyland, Highpoint, and the surrounding neighborhoods (known collectively as “Neighborhood Planning Unit Y,” or NPU-Y) for the next few years, even long after the original grant had expired. In the mid-1990s, it took advantage of the opportunity to apply to CDC for funds to establish a PRC. Applicants were required to have a community partner, and so Morehouse and NPU-Y became applicant partners. The grant was funded, and a community-majority board was created to govern the center. There were still issues to be worked out between the medical school and the community, such as the location of the center and the details of research protocols, but the foundation of trust allowed these issues to be resolved while preserving the partnership (Blumenthal, 2006).

## Take-Home Messages

- Community partnerships are not built overnight. A trusting partnership is developed over months or years.
- A partnership does not depend on a single grant, or even a succession of grants. The partnership continues even when there are no grants.
- A partnership means that resources and control are shared. The academic institution or government agency must be prepared to share funds with the community. The community should be the “senior partner” on issues that affect it.
- Community representatives should primarily be people who live in the community. The programs and projects implemented by agencies, schools, and other entities affect the community, but their staff often live elsewhere.

## Reference

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## ***B. How do you set up and maintain a community advisory board?***

*Tabia Henry Akintobi, PhD, MPH, Lisa Goodin, MBA, Ella H. Trammel, David Collins, Daniel S. Blumenthal, MD, MPH*

Establishing a governing body that ensures community-engaged research is challenging when (1) academicians have not previously been guided by neighborhood experts in the evolution of a community's ecology, (2) community members have not led discussions regarding their health priorities, or (3) academic and neighborhood experts have not historically worked together as a single body with established rules to guide roles and operations. The Morehouse School of Medicine PRC was based on the applied definition of CBPR, in which research is conducted with, not on, communities in a partnership relationship. Faced with high levels of poverty, a lack of neighborhood resources, a plague of chronic diseases, and basic distrust in the research process, community members initially expressed their apprehension about participating in yet another partnership with an academic institution to conduct what they perceived as meaningless research in their neighborhoods.

### **Action Steps**

Central to establishing the Morehouse Community Coalition Board (CCB) was an iterative process of disagreement, dialogue, and compromise that ultimately resulted in the identification of what academicians needed from neighborhood board members and what they, in turn, would offer communities. Not unlike other new social exchanges, each partner had to first learn, respect, and then value what the other considered a worthy benefit in return for participating on the CCB. According to the current CCB chair, community members allow researchers conditional access to their communities to engage in research with an established community benefit. Benefits to CCB members include the research findings as well as education, the building of skills and capacity, and an increased ability to access and navigate clinical and social services. The community has participated in Morehouse School of Medicine PRC CBPR focused on reducing the risk of HIV/AIDS and screening for colorectal cancer. Further, community-based radio broadcasts have facilitated real-time dialogue between metropolitan Atlanta community members and researchers to increase awareness

regarding health promotion activities and various ways that communities can be empowered to improve their health. Other benefits have been the creation or expansion of jobs and health promotion programs through grants for community-led health initiatives.

Critical to maintaining the CCB are established bylaws that provide a blueprint for the governing body. As much as possible, board members should be people who truly represent the community and its priorities. Agency staff (e.g., health department staff, school principals) may not live in the community where they work, and so they may not be good representatives, even though their input has value. In the case of the Morehouse PRC, agency staff are included on the board, but residents of the community are in the majority, and one always serves as the CCB chair. All projects and protocols to be implemented by the PRC must be approved by the CCB's Project Review Committee, which consists of neighborhood representatives. For more than a decade, critical research has been implemented and communities have sustained change. The differing values of academic and community CCB representatives are acknowledged and coexist within an established infrastructure that supports collective functioning to address community health promotion initiatives (Blumenthal, 2006; Hatch et al., 1993).

For more than a decade, critical research has been implemented and communities have sustained change.

### **Take-Home Messages**

- Engagement in effective community coalition boards is developed through multi-directional learning of each partner's values and needs.
- Community coalition boards are built and sustained over time to ensure community ownership through established rules and governance structures.
- Trust and relationship building are both central to having neighborhood and research experts work together to shape community-engaged research agendas.
- Maintaining a community coalition board requires ongoing communication and feedback, beyond formal monthly or quarterly meetings, to keep members engaged.

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Hatch J, Moss N, Saran A, Presley-Cantrell L, Mallory C. Community research: partnership in black communities. *American Journal of Preventive Medicine* 1993;9(6 Suppl):27-31.

### *C. How do you launch a major community-engaged research study with a brand-new partnership that brings together diverse entities and individuals?*

*Mina Silberberg, PhD, Sherman A. James, PhD, Elaine Hart-Brothers, MD, MPH, Seronda A. Robinson, PhD, Sharon Elliott-Bynum, PhD, RN*

## Challenge

As described in an earlier vignette, the African-American Health Improvement Partnership was launched in October 2005 in Durham, North Carolina, with a grant from the National Center for Minority Health and Health Disparities. AAHIP built on the prior work of participant organizations and individuals, but it created new relationships and was a new entity. The lead applicant on the grant was the Duke Division of Community Health (DCH), which had been working with community partners for seven years to develop innovative programs in care management, clinical services, and health education to meet the needs of underserved populations, primarily in Durham.

Until that point, research in the DCH had been limited to evaluation of its own programs, although some faculty and staff had conducted other types of research in their earlier positions. The AAHIP research team included Elaine Hart-Brothers, head of the Community Health Coalition (CHC), a community-based organization dedicated to addressing health disparities by mobilizing the volunteer efforts of Durham African American health professionals. The DCH had just begun working with the CHC through a small subcontract. Because the AAHIP was an entirely new entity, it had no community advisory board (CAB), and although the DCH and other Duke and Durham entities were engaged in collaborative work, no preexisting coalitions or advisory panels had the scope and composition required to support the AAHIP's proposed work.

## Action Steps

The CHC was brought into the development of the grant proposal at the beginning, before the budget was developed, and it played a particularly important role in developing the CAB. The goal was to create a board that represented diverse sectors of Durham's African American and provider communities. On this issue, Sherman A. James (the study PI) and Mina Silberberg (currently the co-PI) deferred to the expertise of Hart-Brothers and Susan Yaggy, chief of the DCH, both of whom had broad and deep ties to the Durham community and years of experience with collaborative initiatives.

The research team decided it would be essential to evaluate its collaboration with the CAB to ensure fidelity to the principles of collaboration, to build capacity, and to help with the dissemination of lessons learned. For this external evaluation, it turned to North Carolina Central University (NCCU), enlisting the services of LaVerne Reid.

When the grant was awarded, it was time to bring together these diverse players and begin work in earnest. Hart-Brothers quickly realized that as a full-time community physician, she could not by herself fulfill CHC's role on the project: to serve as the community "outreach" arm of the research team and participate actively in study design, data collection and analysis, and dissemination. She proposed a budget reallocation to bring on Sharon Elliott-Bynum, a nurse and community activist with a long and distinguished history of serving Durham's low-income community. DCH faculty realized with time that Elliott-Bynum brought to the project unique expertise and contacts in sectors where DCH's own expertise and contacts were limited, particularly the African American faith community. Similarly, Reid, who had recently been appointed interim Associate Dean of the College of Behavioral and Social Sciences at NCCU, recognized that she no longer had the time to evaluate the CAB-research team collaboration on her own and brought in Seronda Robinson from NCCU.

As the work progressed, new challenges arose in the relationship between Duke and the CHC. As a small community-based organization, the CHC used accounting methods that did not meet Duke's requirements or those of NIH; invoices lacked sufficient detail and documentation. Payment to the CHC fell behind, as the DCH returned invoices it had received for revision, and both



parties grew frustrated. The partners decided that the DCH administrator would develop written instructions for the CHC on invoicing for purposes of the grant and train CHC staff on these procedures. Eventually, CHC also brought on a staffer with greater skills in the accounting area.

Duke's lengthy process for payment of invoices frustrated the CHC, which, as a small organization, was unable to pay staff without a timely flow of funds. In response, the research team established that the CHC would tell the DCH immediately if its check did not arrive when expected, and the DCH would immediately check on payment status with the central accounting office. Moreover, the DCH determined that when the CHC needed a rapid influx of funds, it should invoice more frequently than once per month. In this way, through sustained engagement by all parties, the DCH and CHC moved from pointing fingers at each other to solving what had been a frustrating problem. In explaining the AAHIP's capacity to work through these invoicing issues, participants cite not only the actions taken in that moment but also a history of open communication and respect, particularly the inclusion of the CHC in the original budget and the understanding that all members of the research team are equal partners.

### **Take-Home Messages**

- Create the preconditions for solving problems and conflicts through a history and environment of inclusion (particularly with regard to money).
- Recognize and use the unique expertise, skills, and connections of each partner. Step back when necessary to defer to others.
- Be flexible. The study needs will change, as will the circumstances of individual partners.
- Put the right people with the right level of commitment in the right job.
- Commit the staff time required for effective, active community participation on a research team.
- Communicate and invest in capacity building. The operating procedures and needs of academic institutions, federal agencies, and small community-based

organizations are usually very different. As a result, community and academic partners may come to view each other, perhaps mistakenly, as uncooperative. Partners will need to learn each other's procedures and needs and then solve problems together. Community partners are also likely to need capacity building in the accounting procedures required by academic institutions and the federal government.

## 5. OVERCOMING COMPETING PRIORITIES AND INSTITUTIONAL DIFFERENCES

From the concepts of community set forth in Chapter 1 it is apparent that universities can be seen as communities that have their own norms, social networks, and functional sectors. How can we resolve the conflicts and misunderstandings that result when the operations and expectations of universities differ from those of their collaborating communities?

### *A. How do you work with a community when there are competing priorities and different expectations?*

*Karen Williams, PhD, John M. Cooks, Elizabeth Reifsnider, PhD, Sally B. Coleman*

#### **Challenge**

A major priority for the University of Texas Medical Branch at Galveston when developing its CTSA proposal was to demonstrate community partnership with a viable, grassroots community-based organization (CBO). One of the coinvestigators listed on the CTSA proposal was a research affiliate of an active CBO, which was composed of persons representing practically every facet of life in the community. While focusing on its own organizational development, this CBO had identified eight community health needs for its focus and implemented two NIH-funded projects (Reifsnider et al., 2010). The CTSA coinvestigator wanted the CBO to be the community partner for the CTSA proposal, and the other CTSA investigators agreed. The brunt of the active work in the community outlined in the CTSA proposal became the CBO's responsibility. However, although the CTSA work was within the existing scope of work for the community partner, certain invalid assumptions about the type of activities the CBO would do for the CTSA were written into the final version of the grant. Most important, no budget was presented to the CBO that showed support for expected deliverables.

The CBO was unwilling to commit to being a part of the CTSA until the proposal spelled out in detail what it was required to do for the funds. An official meeting took place between selected CBO members and CTSA investigators; after an informal discussion, CBO members gave the university

members a letter requesting specific items in return for their participation. A formal response to the letter was not provided by the university partner; instead, the requested changes were inserted into the proposal and a revised draft circulated to community partners with the assumption that it would address their requests. This was not the understanding of the community partners, and this misunderstanding strained future relationships. The CBO felt that it had not received the answers it had requested, and the university coinvestigator believed that revising the proposal addressed the CBO's requests. The miscommunication persisted for months and resulted in difficulty in establishing the operations of the CTSA once it was funded.

### **Action Steps**

The issue was finally addressed when the university coinvestigator approached the CBO for help in writing another NIH proposal. At that time, it emerged that the CTSA-related issues had never been resolved and that the CBO felt its cooperation was being taken for granted. A meeting was held with the CBO president, another member, and two university researchers who were dues-paying members of the CBO. During this meeting, the misunderstanding was clarified and apologies were offered and accepted. Both the CBO and the university members realized that in a rush to complete grant-writing assignments, shortcuts had been taken that should have been avoided.

### **Take-Home Messages**

- University partners should be clear in responding to written requests from a community for communication about specifics on research collaboration. Communications can be easily misunderstood by well-intentioned individuals. Asking for feedback should be routine practice.
- It is critical for partners to respect and include the input of the community they are trying to serve.
- The lines of communication must remain open until all issues are considered resolved by everyone involved.
- Transparency is always essential for all entities.

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### *B. How do you overcome differences in financial practices between the academic institution and the community?*

*Karen Williams, PhD, Sally B. Coleman, John M. Cooks, Elizabeth Reifsnider, PhD*

## Challenge

Academic research institutions and community organizations often partner on research projects even though they may differ significantly in key ways, including organizational capacity and the types of knowledge considered useful for social problem solving (Williams, 2009). Although evaluation tools exist for assessment of organizational capacity and for setting priorities (Butterfoss, 2007), tools for assessing the “fit” between partnering organizations are scarce. This vignette describes the challenges faced by a CBPR partnership during the preparation and implementation of a joint grant proposal.

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In October 2007, NIH announced the NIH Partners in Research Program. Each application was required to represent a partnership between the community and scientific investigators. Upon award, the grants were to be split into two separate but administratively linked awards. A community health coalition and university health science center that had worked together for several years submitted a joint proposal. Preparing the budget for the joint proposal highlighted power imbalances in the community-academic partnership. The university-based investigators’ salaries were large relative to the salary of the community-based PI, which was based on what he earned as an elementary school music teacher. To direct more funds to the community partner, the partnership minimized the university-based investigators’ time on the project and allocated all non-salary research funds to the budget of the community partner. This resulted in a

30% community/70% university split of direct costs. In addition, every dollar of direct cost awarded to the university partner garnered an additional 51 cents, because the university had negotiated a 51% indirect cost rate with NIH. However, the community partner received no indirect cost add-on because it had no negotiated rate with NIH. The irony in allocating program funding to the community partner was that this sharing gave the community partner more administrative work to do, even though the partner received no support from indirect costs.

A second challenge arose that highlighted the difference in expectations between university and community partners. The grant required that community workers facilitate discussion groups. To accomplish this, the community portion of the budget had to pay to train community workers and trainees as well as cover costs such as meeting rooms, food, and materials. Inevitably, the community's small pool of funds was exhausted, and some university funds were required. Getting community researchers and research expenses paid by the university took a month or longer. University faculty are accustomed to lengthy delays in reimbursement, but community members expect prompt payments. Both the community-based and university-based PIs were put in the uncomfortable position of having to continually ask those waiting for payment to be patient. Documentation procedures were not as extensive and wait times were shorter when community research funds flowed through the community organization.

A second challenge arose that highlighted the difference in expectations between university and community partners.

### **Action Steps**

It would have been administratively easier for the university partner to pay the community partner on a subcontract. However, this arrangement was prohibited by NIH because the purpose of the Partners in Research grant was to establish an equal partnership. In future CBPR projects, the community partner may consider subcontracting as a way to decrease administrative burden, even if it decreases control over research funds. Also, the university-based PI should have more thoroughly investigated the procedures for university payments, alerted community members to the extended wait times for payments, and advocated for streamlined procedures with university administration and accounting.

## Take-Home Messages

- “Splitting budgets in half” is too blunt a tool for the delicate work of building equal partnerships. Exploring more nuanced mechanisms to balance power between community and academic partners is critical.
- Make no assumptions about the capabilities of the institution (university or CBO) or how it functions.
- University and CBO partners need to come to agreement on all processes and timetables that might be involved.
- Foster open communication with those affected to maintain organizational and personal credibility.

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### *C. How do you harness the power and knowledge of multiple academic medical institutions and community partners?*

*Carolyn Leung Rubin, EdD, MA, Doug Brugge, PhD, MS, Jocelyn Chu, ScD, MPH, Karen Hacker, MD, MPH, Jennifer Opp, Alex Pirie, Linda Sprague Martinez, MA, Laurel Leslie, MD, MPH*

## Challenge

In some cases, several CTSA sites are clustered in a small geographic area and thus may be well suited to demonstrating how institutions can overcome competitive differences and work together for the good of their mutual communities.

In the Boston metropolitan area, three CTSA sites, Tufts University, Harvard University, and Boston University, prioritized working with each other and with community partners.

### **Action Steps**

To facilitate their collaboration, the three sites took advantage of the CTSA program's Community Engagement Consultative Service, bringing two consultants to Boston to share insights about forming institutional partnerships in an urban area. Bernadette Boden-Albala from Columbia University in New York City and Jen Kauper-Brown from Northwestern University in Evanston, Illinois, visited Boston on separate occasions and shared their experiences in bringing together CTSA sites and community partners in their areas.

These visits helped to facilitate conversation among the three CTSA sites about how to work together for the mutual benefit of the community. At the same time, the CTSA sites each were having conversations with their community partners about the need to build capacity for research in the community. When a funding opportunity arose through the American Recovery and Reinvestment Act of 2009, the three CTSA sites, along with two critical community partners, the Center for Community Health Education Research and Services and the Immigrant Services Providers Group/Health, decided to collaboratively develop a training program to build research capacity.

Of the 35 organizations that applied for the first round of funding, 10 were selected in January 2010 to make up the first cohort of community research fellows. These fellows underwent a five-month training course that included such topics as policy, ethics, research design, the formulation of questions, and methods. The community organizations represented in the training varied in size, geographic location, and the types of "communities" served (e.g., disease-specific advocacy organizations, immigration groups, and public housing advocacy groups specific to certain geographic boundaries). The program used a "community-centered" approach in its design, feedback about each session was rapidly cycled back into future sessions, and learning was shared between community and academic researchers. The first cohort concluded its work in 2010. Outcomes and insights from the project will feed the next round of training.



Although the CTSA sites in the Boston area were already committed to working together, bringing in consultants with experience in working across academic institutions helped them think through a process and learn from other regions' experiences. The consultants affirmed that, by working together, academic medical centers can better serve the needs of their mutual community rather than the individual needs of the institutions. This was echoed by participants in the capacity-building program described above. One clear response from participants was their appreciation that the three academic institutions partnered to work with communities rather than splintering their efforts and asking community groups to align with one institution or another.

### **Take-Home Messages**

- Research training programs need to model multidirectional knowledge exchange; the knowledge of community members must be valued and embedded into the curriculum alongside academic knowledge.
- Transparency, honesty, and sharing of resources (fiscal and human) among academic institutions and community groups are crucial to building trust.
- Academic institutions can and should work together on the common mission of serving their communities. Outside consultants can help facilitate multi-institutional collaboration.

## **CONCLUSION**

The vignettes presented here illustrate key challenges in CEnR and provide examples of how partnerships have dealt with them. Ultimately, what underpins the solutions presented here are the same ideals encapsulated in the principles of community engagement — clarity of purpose, willingness to learn, time, understanding differences, building trust, communication, sharing of control, respect, capacity building, partnership, and commitment.