# PARTNERING WITH COMMUNITY-BASED ORGANIZATIONS: AN ACADEMIC INSTITUTION'S EVOLVING PERSPECTIVE

**Background:** Community-based participatory research (CBPR) is ideally a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings.

**Methods:** We reviewed the processes, strategies, and activities around the interface of community-academic partnerships using a CBPR model focused on addressing healthcare issues for minority elders.

Results: Key challenges for the community side include understanding: 1) the needs of the academic partner; 2) how to assess whether there are shared values, goals, and research priorities; 3) the limits of one's organization and competing demands; 4) how to use the partnership to build community capacity to conduct research; and 5) the value added for the community from involvement in research versus the risks inherent in participation. Key challenges for the academic side of the partnership include understanding: 1) what community is; 2) the value added by a true partnership; 3) how to build effective relationships; 4) what a balanced collaboration with equal power sharing entails; 5) that community partner goals may not mirror academic goals; 6) the capabilities and limits of community partners; and 7) how to effectively use a community advisory board (CAB). Building relationships and effective collaboration require time, patience, physical presence, respect, and commitment-elements frequently in short supply in a busy academic environment. A memorandum of understanding (MOU) can be an important tool to document roles and responsibilities. The community advisory board (CAB) is an important liaison between the community and academic settings but is not sufficient to constitute a partnership in and of itself. Members should be carefully selected so that the CAB can assist in: 1) creating a partnership roadmap; 2) providing contacts and strategies; 3) helping to broker competing agendas; 4) helping provide a balance in articulating the community health priorities; 5) giving additional perspectives and balance for the partnerships; and 6) participating as a critical component of the mentor pool.

**Conclusion:** Our evolving perspective on CBPR has reinforced the importance of a MOU to document the roles and expectations of each partner and a carefully selected CAB to develop and enhance true collabora-

Keith C. Norris, MD; Rebecca Brusuelas, BA; Loretta Jones, MS; Jeanne Miranda, PhD; O. Kenrik Duru, MD, MSHS; Carol M. Mangione, MD, MSHS

tion with community partners. We cannot overemphasize the importance of educating academia to truly value the role of community and resident experts as equitable and necessary partners to most effectively perform quality research and ultimately bring evidenced-based care for diverse elderly communities into a real-life setting. (*Ethn Dis.* 2007;17[suppl 1]:S1-27–S1-32)

**Key Words:** Community-Based Participatory Research, Healthcare, Elders

From the Departments of Medicine, Charles R. Drew University (KCN); David Geffen School of Medicine, UCLA (KCN, RB, JM, KD, CMM); Healthy African American Families (LJ); UCLA School of Public Health (CMM), Los Angeles, California.

Address correspondence and reprint requests to Keith C. Norris, MD; Charles R. Drew University; 11705 Deputy Yamamoto Place, Suite B; Lynwood, CA 90262; 323-249-5711; knorris@ucla.edu

## INTRODUCTION

Despite remarkable advances in biomedical sciences and medical therapeutics in recent decades, the anticipated improvements in patient outcomes have not been realized because emerging research advances have not been translated into clinical practice.<sup>1</sup> Indeed, as many as one half of Americans with major chronic diseases, such as diabetes or depressive disorders, do not receive care that meets recommendations for acceptable practice.<sup>2–4</sup> Health status disparities experienced by older, socioeconomically disadvantaged persons and racial/ethnic minorities continue to be a major challenge to the US healthcare system.<sup>5–8</sup>

For several reasons, the scientific evidence needed to improve the health of minority communities is limited. The evidence base that informs healthcare practices has rarely included adequate samples of ethnic minorities to draw firm conclusions with regard to these groups.9 Moreover, racial and ethnic disparities in health care are increasingly recognized as occurring in the context of broad historic and contemporary social and economic inequality.<sup>10</sup> Thus, health interventions for these communities must encompass the full spectrum of needs of the minority elderly community in order to produce sustained health improvements.

One approach to improving clinical outcomes is an active partnership of community and academia to create relevant and methodologically sound investigations, and ultimately evidencebased recommendations that are embraced and promoted by the communities we serve.<sup>11</sup> This integrated process

for improving health outcomes has been termed community-based participatory research (CBPR).<sup>12–14</sup> At an operational level, we embrace the CBPR model as "a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings."15 Fundamental characteristics of CBPR identified by Israel et al include the following: 1) recognizes community as a unit of identity; 2) builds on strengths and resources within the community; 3) facilitates collaborative, equitable partnership in all phases of the research; 4) promotes co-learning and capacity building among all partners; 5) integrates and achieves a balance between research and action for the mutual benefit of all partners; 6) emphasizes local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health and disease; 7) involves systems development through a cyclical and iterative process; 8) disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process; and 9) involves a long-term process and commitment.<sup>12</sup> Despite this description, it is common for many relationships labeled CBPR to actually represent traditional academic research activities that are placed in the community with a "base" at a community site, but the determination of health needs, research design, data collection, analysis and interpretation, and dissemination reside with the academic arm. Thus, we sought to develop and maintain an equitable and highly engaged partnership that recognizes and respects each partner, yet clearly distinguishes the two in order to minimize false expectations and potential conflicts. We describe our experience in creating this partnership with a focus for improving the healthcare of minority elders, and the key elements we have identified, as critical to sustaining this relationship.

## **METHODS**

We reviewed the processes, strategies, and activities around the interface of a community-academic partnership grounded in a highly engaged CBPR model focused on addressing healthcare issues for minority elders. The major community partners included Healthy African American Families (HAAF), the Los Angeles Department of Health Services (LADHS), and several key churches and senior centers. Healthy African American Families (HAAF) is a nonprofit, community-based organization whose mission is to improve the health outcomes of African American and Latino communities in Los Angeles County by enhancing the quality of care and advancing social progress through education, training, and collaborative partnering with community, academia, researchers, and government. Originally developed in 1992 with funding by the Centers for Disease Control, HAAF is unique in that its mission is to be a "broker" around education and collaborative partnering, rather than having a special service requirement. The LADHS has a public health mission to the citizens of Los Angeles. Los Angeles is divided into eight service planning areas (SPAs); area health offices within LADHS are focused on planning public health and clinical services according to the health needs of local communities. Service planning areas (SPAs) 5 and 6 share a common health officer and represent the county service areas that contain UCLA and Drew University, respectively.

The academic partners include faculty members from the David Geffen School of Medicine at UCLA and Charles R. Drew University of Medicine and Science, most of who are members of the National Institutes of Health-funded UCLA/Drew Resource Center for Minority Aging Research (RCMAR) Center.

The concept of community has diverse meanings and can refer to

a geographic area, a community-based agency (ie, schools, religious organizations), or related values and norms (such as African American culture). For the RCMAR project, we define community as a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings, as posited by Hatch et al.<sup>13</sup>

## RESULTS

Overall, developing and building true equitable and transparent partnerships was a rewarding experience for all partners, but this process had struggles and periods of tension. The high level of interaction was deemed extremely educational and valuable to all participants. The partnership enhanced recruitment and retention for randomized eldercare studies, which provided an avenue for older persons to have input on potential research projects to address their needs, allowed streamlined community-level feedback on a regular basis, and played a key role in the selection and mentoring of entry-level faculty who were affiliated and supported by the UCLA/Drew RCMAR to learn how to conduct partnered research with older persons from under-represented minority groups. Our recommendations based on this experience for community-academic partnerships are shown in Table 1. During the process, key challenges were also identified that we have stratified into domains of the community and academic sides of the partnerships.

## **Community Side**

Key challenges noted for the community side include understanding: 1) the needs of the academic partner; 2) how to assess whether the values, goals, and research priorities are truly shared; 3) the limits of existing organizational capacity and resources, as well as competing demands for those resources;

#### Table 1. Recommendations for community-academic partnerships

Develop a memorandum of understanding to define roles of the partnership around issues such as process/procedure, perspective, and time parameters. Do not enter into partnership with assumptions.

Value community "resident experts."

Establish community advisory boards; they are important but are not sufficient for partnerships.

Understand how to collaborate and build effective relationships: commitment = time, patience, physical presence, and assistance in building the communities' capacity for understanding, participating in, and benefiting from research.

Faculty need to be briefed/educated by community leaders and visa versa.

Recognize the existence of competing agendas - be open, respectful.

Respect community's time, effort, insights (recognized with payment for services, authorship, etc. - same as academia).

Build on existing community resources.

Funding source should be committed to maintaining close contact throughout the project.

For meetings, alternate sites, establish ground rules, maintain community academic co-chairs (consider two community co-chairs in many settings to lessen the chance that the community will be dominated by academia).

Mentorship: Use a model where community members are co-mentors for entry-level academic faculty who are learning skills to conduct respectful partnered research with and in communities with balanced input from both academic and community sides of the research program.

4) how to use the partnership to build organizational/community capacity to conduct research; and 5) the value added for the community from involvement in research versus the risks inherent in participation. Community partners offered guidelines to modify academic behaviors that were perceived as unhelpful to the CBPR process (Table 2). Community partners also voiced a desire for more education regarding the research process.

#### Academic Side

For the academic side of the partnership, key challenges include understanding: 1) the meaning of community; 2) the value added by a true partnership; 3) how to build effective relationships; 4) what a balanced collaboration with equal power sharing entails; 5) that community partner goals may not mirror academic goals; 6) the capabilities and limits of community partners; and 7) how to effectively work with a community advisory board (CAB). Building relationships and effective collaboration require time, patience, physical presence, respect, and commitment - elements frequently in short supply in a busy academic environment (Table 3). Without the commitment of resources and incentives (eg, academic promotion) to building such partnerships, true collaborations cannot be created. A memorandum of understanding (MOU) is important to document roles and responsibilities (appendix – sample MOU).

#### **Community Advisory Board**

The community advisory board (CAB) is a liaison between the community and academic settings, but it cannot be considered a true partnership by itself.<sup>16</sup> Community advisory board (CAB) members should be carefully selected so that the CAB can assist in: 1) creating a effective roadmap for the partnership; 2) providing key contacts and related strategies; 3) brokering competing agendas between the partners; 4) helping to provide balance in articulating community health priorities; 5) giving additional perspectives and balance for the partnerships; and 6) participating in a mentor pool, not only to assist in the selection and development of junior faculty, but also in the ongoing education for senior academic faculty around effective community partnering. The community advisory board (CAB) provides an opportunity for building strong community linkages that extend beyond the primary partners. Such linkages are pivotal to generate community input and provide early community feedback at multiple levels, as more robust systems of partnership are established.<sup>17-19</sup> Kev advice for research with older persons provided by our CAB included recruitment strategies, culturally sensitive approaches toward engagement, and learning how to share results with the

#### Table 2. Community suggestions for modifying academic behaviors

Body Language	Verbal: Avoid	Verbal: Use
ooking bored	Your community	This community
lot touching	I know what you mean	I can relate
lot making eye contact	I understand where you're coming from	I can empathize with you
lot participating in discussions	My data	Data collected in the community
Being enthusiastic about academic activities but apa- thetic about community activities	You people	This community

Table 3.	Considerations fo	r enhancing the	academic side of	community-academic	partnerships

Ensuring an understanding of community as a partner Appreciating the value added by a true partnership Learning how to build effective relationships with community Investing in community to enhance its ability to function as a more highly effective partner

Learning how to develop balanced collaborations with equal power sharing Understanding that community partner goals are unlikely to mirror academic goals Recognizing the capabilities and limits of community partners Understanding how to effectively utilize a community advisory board

participating community and other key stakeholders for the study's findings. Table 4 highlights some of the key elements of an effective CAB.

## DISCUSSION

Our evolving perspective on CBPR has reinforced the importance of several key elements in moving beyond performing research that is merely placed or based in the community to creating a process to establish an equitable partnership. While CBPR ideally involves community in all or most phases of the research process, in practice researchers have narrowed this definition. Many academic researchers consider research set in a community rather than a hospital clinic as sufficient to warrant the designation CBPR. In many instances, the research question and research design have already been determined and conducted in a community setting with periodic reports presented to a community advisory board. In this approach, the community does not actively participate in the conduct of research.

A critical review of the barriers and facilitators of community participatory and other forms of community-level translational research has identified several major challenges to the academic/community partnership strategy.<sup>12,20</sup> Barriers that reaffirm our institutional findings include 1) lack of trust and perceived lack of respect between researchers and community members secondary to a consistent history of research with no direct community benefit and no feedback of results to community; 2) inequitable distribution of power and control in academic/ community and agency/community partnerships in which both control and the distribution of resources-infrastructure, information, and technical expertise-overwhelmingly favor the non-community partner; 3) conflicts associated with differences in priorities, perspectives, assumptions, values, and beliefs of researchers versus community members often reflected in incongruent objectives and dynamic tensions (eg, scholarly research versus community change); 4) inordinate and competing time demands (the substantial expenditure of researcher time

needed to establish and maintain genuine community relationships far exceeds the time that would be allocated to equivalent non-community academic projects); and 5) devaluation of contributions by community members because the time applied to these same projects by community members is typically uncompensated.

To address many of these issues, Jones and colleagues described several elements as key to developing a functional partnership, including creating equal partners; defining the community as a partner; participating in building the communities' capacity for understanding, participating in, and benefiting from research; and the commitment of the funding source to maintain close contact throughout the length of the project.14,21

This type of highly engaged equitable community partnership model of CBPR is particularly important for older minority communities who are substantially underrepresented in most interventional studies and who present unique health issues linked to gender, culture, and generational diversity. Un-

Networking	Vision	Intangibles	
Help create a partnership roadmap	Establish an honest overview of the short- and long-term plans	Integrate CAB members as co-mentors for all aspects of faculty development	
Help provide balance in articulating community health priorities	Choose to be informed and updated on a regular basis in one or more formats (eg, briefings, emails, conference calls, meetings)	Seek appropriate community co-mentors for entry-level faculty	
elp broker competing agendas Solicit and support recommendations and critiques, similar to academic input		Financially compensate community members for their participation much as the academic partners would be paid.	
Provide contacts, strategies	Provide perspectives and balance for the partnerships		

derstanding the implications of these factors on traditional evidence-based interventions is critical to improve care for the elderly in real-life settings. The community partnership model of CBPR is not easy to implement.<sup>22</sup> Over the last 10 years of highly interactive collaboration, including many discussions, arguments, and frustrations on both the community and the academic side, our community-academic partnership has only recently matured to a more highly functional, ongoing, collaborative process between key community partners and academic partners, joined by MOUs, working with a carefully selected CAB, and participating in high levels of bi-directional engagement.

Within this framework, both sides are clear about the details of the research activities and recognize the value of these activities to the community. In addition, the community has participated in the selection of key elder priority areas, research questions, study designs and analyses, interpretations of the assessment of interventions, dissemination of research results, the selection and co-mentoring of scholars and entry-level faculty affiliated with our center. Our institutional experience reinforces our community partners' insights into the importance of educating academia to respect and value the role of community and resident experts as equitable and necessary partners. Such respect is vital in order to most effectively perform quality translational research and ultimately transform evidence-based care for diverse elderly communities into improved patient outcomes.

Our experience also affirms that researchers should not assume that a community will immediately respond to an opportunity to collaborate in a community-based research project. This hesitation results from a history of mistrust of the research community, uncertainty as to the direction the research or partnership may take, and doubt concerning the community's status as partners. In addition, the community may hesitate if they believe they are not privy to the entire process.<sup>14</sup>

At the institutional level, several important transformations must occur to support the growth and development of the next generation of well-trained faculty to engage in community-partnered aging research. Promotions committees and department chairs need to embrace community-based research; it is an emerging National Institutes of Health priority area in the translation of evidenced-based trials to improving clinical outcomes. Recognition of the challenges and importance of establishing relationships, and the impact on the development of scientific publications in a traditional academic tenure track, may necessitate the development of alternate metrics of academic progress if we are serious about developing the pool of faculty that can truly affect the health of older persons.

Ultimately, community-partnered interventions for older persons who are African Americans and Latinos will: 1) enhance the validity and quality of the research by incorporating the knowledge of the people involved; 2) bridge cultural gaps that may exist between the partners involved; 3) incorporate cultural, social, and economic factors into strategies that may influence health; 4) facilitate the design of culturally sensitive and linguistically appropriate measures and methods; 5) provide resources and opportunities for the communities involved; 6) disseminate information and communicate with the public and interested groups on health and research advances and on new directions for aging healthcare and research; and 7) develop and promote faculty with the skills and values needed to conduct partnered translational research with communities who have historically not been included in such endeavors.

#### REFERENCES

 Lenfant C. Clinical research to clinical practice—lost in translation? N Engl J Med. 2003; 349:868–874.

- McGlynn EA, Asch SM, Adams J, et al. The quality of health care delivered to adults in the United States. N Engl J Med. 2003;348: 2635–2645.
- 3. Young AS, Klap R, Sherbourne DC, Wells KB. The quality of care for depressive and anxiety disorders in the United States. *Arch Gen Psychiatry.* 2001;58:55–61.
- Garfield SA, Malozowski S, Chin MH, et al. Considerations for diabetes translational research in real-world settings. *Diabetes Care*. 2003;26:2670–2674.
- Kramarow E, Lentzner H, Rooks R, Weeks J, Saydah S. *Health and Aging Chartbook*. Hyattsville (Md): National Center for Health Statistics; 1999.
- Finley C, Gregg EW, Solomon LJ, Gay E. Disparities in hormone replacement therapy use by socioeconomic status in a primary care population. *J Community Health.* 2001;26(1): 39–50.
- Bierman AS, Clancy CM. Health disparities among older women: identifying opportunities to improve quality of care and functional health outcomes. *J Am Med Womens Assoc.* 2001;56(4):155–159.
- Wallace SP, Villa VM, Enriquez-Haass V, Mendez CA. Access is better for racial/ethnic elderly in Medicare HMOs—but disparities persist. *Policy Brief UCLA Cent Health Policy Res.* 2001;(PB2001-2):1–4.
- Mission statement. National Institute on Aging. Available at: www.nih.gov/nia/stratplanhd/2000-2005/. Accessed on: 6/15/2005.
- Institute of Medicine. Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Washington: National Academy Press; 2002.
- Wallerstein N. Commentary: challenges for the field in overcoming disparities through a CBPR approach. *Ethn Dis.* 2006;16(1)Suppl 1:S146–S148.
- 12. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health.* 1998;19: 173–202.
- Hatch J, Moss N, Saran A, Presley-Cantrell L, Mallory C. Community research: partnership in Black communities. *Am J Prev Med.* 1993;9(Suppl 6):27–31.
- Jones L. Partnership building. In: O'Fallon LR, Tyson FL, Dearry A, eds. Successful models of community-based participatory research. Research Triangle Park (NC): National Institute of Environmental Health Sciences, 2000;35– 41, Available at www.niehs.nih.gov/translat/ cbr-final.pdf. Accessed on 4-11-05.
- Conference on Community-Based Participatory Research. November 27–28, 2001. The Agency for Healthcare Research and Quality. W.H. Kellogg Foundation, the Office of

### PARTNERING WITH COMMUNITY-BASED ORGANIZATIONS - Norris et al

Minority Health, US Department of Health and Human Services, the Office of Behavioral and Social Sciences Research, the National Institutes of Health. Rockville, Md. Available at: www.ahrq.gov/about/cpcr/cbpr1.htm. Accessed on 11/2/06.

- Brieland D. Community advisory boards and maximum feasible participation. *Am J Public Health.* 1971;61(2):292–296.
- Poindexter CC, Lane TS. Choices and voices: participation of people with HIV on Ryan White Title II Consumer Advisory Boards. *Health Soc Work.* 2003;28(3):196–205.
- Strauss RP, Sengupta S, Quinn SC, et al. The role of community advisory boards: involving communities in the informed consent process. Am J Public Health. 2001;91(12): 1938–1943.
- Morin SF, Maiorana A, Koester KA, Sheon NM, Richards TA. Community consultation in HIV prevention research: a study of community advisory boards at 6 research sites. *J Acquir Immune Defic Syndr.* 2003;33(4): 513–520.
- Yarborough M, Sharp RR. Restoring and preserving trust in biomedical research. *Acad Med.* 2002;77(1):8–14.
- Stockdale SE, Mendel P, Jones L, Arroyo W, Gilmore J. Assessing organizational readiness and change in community intervention research: framework for participatory evaluation. *Ethn Dis.* 2006;161(Suppl 1):S136– S145.
- 22. Wells KB, Staunton A, Norris KC, et al. Building an academic-community partnered network for clinical services research: the

community health improvement collaborative (CHIC). *Ethn Dis.* 2006;16:S3–S17.

#### AUTHOR CONTRIBUTION

- Design concept of study: Norris, Jones, Brusuelas, Miranda, Mangione
- Acquisition of data: Norris, Jones, Brusuelas, Miranda, Duru, Mangione
- Data analysis and interpretation: Norris, Jones, Brusuelas, Miranda, Duru, Mangione
- Manuscript draft: Norris, Jones, Brusuelas, Miranda, Duru, Mangione
- Acquisition of funding: Mangione, Norris, Miranda
- Administrative, technical, or material assistance: Miranda, Mangione, Norris Supervision: Mangione, Norris, Miranda

## Appendix. Sample Memorandum of Understanding

Service Planning Area 6 and Healthy African American Families (HAAF II) agree to collaborate to address the reduction and impact of Infant mortality and morbidity in the African-American community throughout. SPA 6 by the mutual sharing of information, educational strategies, and health promotion strategies and facilitate capacity building.

SPA 6 is a Service Planning Area comprised of regions within the southern portion of Los Angeles County. Over the past 2 1/2 years, the SPA 6 Collaborative group has grown to include Parent representatives, kinship caregivers, CBOs, LA County departments (i.e. Department of Children and Family Services, Department of Health Services, Department of Mental Health, Department of Probation, and Department of Public Social Services), school administration (LAUSD and LACOE), community businesses, advocacy groups, youth and concerned citizens. The collaborative group functions to help identify and fill gaps in services, share information about issue facing SPA 6 communities and constituents, and network.

SPA 6 agrees to:

- Participate in the one-year comprehensive planning for an Infant Mortality and Morbidity Prevention Project in partnership with HAAF and the Centers for Disease Control.
- Support the fundraising efforts to expand services for families at risk for Infant Mortality.
- Assist in the design of programs and services which will reduce unnecessary deaths and preventable disabilities among African-Americans; and
- Cooperate with the evaluation and research efforts to ensure that effective modes are well documented and replicable.

HAAF II agrees to:

- Provide the structure, information, data, and staff to implement goals and objectives of the one-year planning process.
- Organize the SPA 6 regional coalition to include health professional, consumers, and advocates, medical and academic institution and city/ county/state health department officials.
- Share the data and strategies derived from the process with all members of the SPA 6 regional coalition; and
- Evaluate the community collaborative effort.

The period of this collaboration will be September 1, 1999 to August 30, 2000.

Agreed to this \_\_\_\_\_ day of June, 1999

Margo Wainwright, Co-Convener, SPA6

Loretta Jones, Project Director, HAAF II