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Practical Tips for Establishing Partnerships with Academic Researchers: A Resource Guide for Community-Based Organizations

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Abstract

Background—Research exists on strategies for successful conduct of community-based participatory research (CBPR). Unfortunately, few published resources are available to advise community-based organizations (CBOs) on preparation for and engagement in CBPR.

Objectives—We aimed to create a resource for CBOs that describes how an organization can prepare for and participate in CBPR.

Methods—We used a case study approach of one CBO with a decade-long history of collaboration with academic researchers. We identified lessons learned through a retrospective review of organizational records and the documentation of experiences by CBO leadership and research partners. The findings were then labeled according to CBPR Partnership Readiness Model dimensions.

Lessons Learned—The review of CBO documents and key informant interviews yielded ten practical tips to increase organizational readiness for and engagement in CBPR.

Conclusions—By understanding the best practices for organizational readiness for and participation in CBPR, CBOs will be better equipped to actively participate in community-academic partnerships.

Keywords

Community-Based Participatory Research; Community health partnerships; Community health research; Health disparities; Health outcomes

INTRODUCTION

Research exists on strategies for successful conduct of community-based research and for establishing effective community-academic partnerships.^{1–5} In addition, a growing body of literature highlights the value of community-based organizations' (CBOs) involvement in

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research. CBOs advocate for a focus on relevant questions around service provision and the health of the community to improve the real-world application of interventions. For example, cancer control research targeting underserved populations has benefited from interventions developed and delivered through community-based participatory research (CBPR), which is often conducted in collaboration with CBOs.⁶⁻⁹ Despite this potential, CBOs often lack clear guidance on how to prepare for or engage in research, and few published resources are available on how to establish organizational readiness for and participate in CBPR. Recent efforts to bridge some of these gaps include the work by Andrews and colleagues with their CBPR Partnership Readiness Model.² This model outlines three primary dimensions that support readiness to engage in CBPR of CBOs and academic researchers: goodness of fit, capacity, and operations. From a community-based perspective, each of these dimensions relates to the necessary actions of a CBO to participate fully in research. For instance, under *Goodness of Fit*, Andrews and colleagues consider having shared values and acknowledgement of mutual benefits as necessary indicators for a successful community-academic partnership.² However, prior to identifying a suitable academic partner, a CBO needs to identify the values and potential research-relevant questions the CBO has regarding service provision or the population it serves. Likewise, a review of a CBO's organizational *Capacity*, including leadership practices, competencies, and resources, is critical to engaging in CBPR. Examining capacity allows an organization to recognize its own strengths and limitations based on staff availability and other resources. It also helps CBOs determine how much involvement with research is realistic and what the organization brings to the table when establishing partnerships. *Operations*, as outlined by Andrews and colleagues,² includes transparent communication, which is necessary not only between CBOs and academic researchers but also within a CBO to ensure staff members are engaged with and supportive of the research goals.

The purpose of this paper is to outline specific and actionable tips for CBOs to prepare for and participate in CBPR. To accomplish these aims, we conducted a case study through a retrospective records review and documentation of experiences of an active and established CBO engaged in CBPR (Nueva Vida, Inc.). Using the partnerships with researchers at Georgetown University and other institutions as exemplars, we illustrate practical applications of our recommendations to CBOs on how to plan for and contribute to CBPR, addressing challenges throughout. Under each tip, we include questions a CBO can reflect upon and answer prior to and during partnerships with academic researchers.

APPROACH

We focus the current case study on the experiences of Nueva Vida, Inc. (NV), a CBO with a mission to inform, support, and empower Latinas affected by cancer in addition to advocating for and facilitating access to state-of-the-art services throughout the cancer continuum.¹⁰ NV was founded in 1996 with the goal of reducing health outcome disparities among Latinas, including low cancer screening rates¹¹ and poorer quality of life among cancer survivors.¹² NV provides Latinas at risk for cancer and Latina cancer survivors with tools to navigate the health care system and improve their quality of life through culturally competent services. These services include breast and cervical cancer awareness education, individual and group therapy for survivors, and patient navigation services for access to

cancer screening, diagnostic, and treatment services. The organization reaches over 4,000 individuals and their families annually, and has served over 1,000 Latina cancer survivors in the Washington, DC, Baltimore, MD, and Richmond, VA, metropolitan areas since its inception. Throughout all programs, NV serves a diverse population, both in country of origin and socioeconomic status: 88% of NV's clients are uninsured, 82% speak little to no English, and 44% have an elementary school education or less.

Since 2000, NV has collaborated with researchers, including those at Georgetown University, on the implementation and publication of critical studies that have helped fill the gap on much needed research related to cancer disparities among Latinas.^{6, 8, 9, 13, 16, 17, 18} The organization's accomplishments and capacity in CBPR include collaboration on seven studies with academic researchers, six publications (with additional publications in process or under review), and systematic data collection and impact evaluation of the organization's service model (See Table 1). NV's role in research partnerships grew over time, reaching the point of proposing study projects to potential academic partners. In each of these studies, researchers at Georgetown or other institutions were the principal investigators (PI). Staff at NV served as site PIs, contributed to study design and assessment, and helped recruit participants; NV board members have served on the advisory boards for these projects.

We conducted the present case study using a retrospective review of organizational records and documentation of the experiences of NV's leadership and academic research partners. We completed a content review of existing records, led by a co-first author (FG) and reviewed by the senior author (LC), both of whom served in leadership capacities at NV at the time of the record review. The existing records consisted of abstracts and conference presentations, annual reports documenting the CBO's growth, service proposals, and minutes from meetings with academic partners. Research staff and assistants at NV compiled these documents; materials were selected for inclusion in the content review if they related to research activities and were completed from 2000 to 2012. We excluded materials that focused solely on service provision of the organization. Guided by the experiences of NV's successful research collaborations and existing CBPR theoretical models,² two team members (FG and LC) searched for themes related to preparation for and participation in CBPR partnerships from the perspective of a CBO. The two team members then revised and refined the identified themes through an iterative discussion process to reach agreement about major themes. Disagreements were resolved through consensus discussion with the entire team. These team discussions then led to the identification of the practical tips to help CBOs operationalize the identified themes. In addition, team discussions ensured that the findings matched the perspectives of all individuals engaged in the existing partnership. Specifically, we sought to highlight: the strategies used by NV to prepare and engage in successful CBPR partnerships; the process of contributing to research collaborations; and objectives of collaborative research from a CBO perspective. Our review of these documents and identification of themes yielded ten practical tips for how CBOs can establish organizational readiness for and maintain engagement in CBPR. We again used an iterative process to clarify and revise the identified tips to distinguish concrete actions that could be useful to CBOs. These findings were then labeled according to the dimensions of the CBPR Partnership Readiness Model described by Andrews and colleagues² of goodness

of fit, capacity, and operations, providing greater context as to a CBO's capabilities for research.

ESTABLISHING ORGANIZATIONAL READINESS FOR CBPR

We have detailed ten specific tips a CBO can implement to plan for and take part in CBPR. Below we identify each tip, provide examples where applicable, and highlight questions that CBOs can reflect upon to determine their readiness for CBPR collaborations with academic researchers.

1. Recognize the CBO's value to research in its service provision and existing engagement with the community, and its expertise in these areas. (Identifying Goodness of Fit, Capacity)

One of the foremost strengths of a CBO—both in its own right and in CBPR engagement—is its in-depth knowledge of the community it serves. Feedback from NV's staff indicated they felt they had little to contribute during discussions about research interventions, particularly if they had not had formal research training. However, through their direct work with the community, CBO staff has expertise in the cultural values and practical needs of the community it serves. This is valuable knowledge for any research study. For example, experience working with the target community can help influence the design or outcomes of a research intervention, as well as troubleshoot difficulties throughout implementation.

Upon recognizing its expertise, a CBO can more fully appreciate the financial value of its contributions to research partnerships. CBOs should consider the value of staff time and expertise, as well as costs associated with the physical space used for research activities, relevant supplies/equipment, and project-related travel expenses. The CBO's familiarity with the community being served is valuable and should be appropriately recognized in terms of financial support.

- What are the CBO's organizational strengths and what do they bring to a CBPR partnership?
- How does the CBO's expertise translate into financial value?

2. Identify research-relevant questions that are important to the CBO's community and clients it serves. (Goodness of Fit)—From NV's experience, the questions that generated community-academic partnerships were often driven by client behavior patterns observed by staff, report findings from client demographic data, a lack of information in the literature, or a desire to understand program effectiveness. The most important factor when identifying questions to evaluate is to ensure that they are grounded in experience and will improve either the understanding of the client population or direct service provision. For example, NV noticed that its clients (consisting largely of Latina breast cancer survivors) often lacked confidence in their ability to communicate with their health care team. As part of regular service provision, NV's clinical staff and patient navigators would help survivors build this skill. NV wanted to learn more about the impact of this support. Thus, NV talked with an academic partner at The Catholic University of America to help investigate within a research context.¹³

- What long-term goals or impact does the CBO aim to achieve through service provision?
- What trends or observations has staff noted about programs or characteristics of clients?
- Considering these goals and observations, what types of services or client characteristics would the CBO like to know more about?

3. Keep the needs of clients a first priority. (Capacity)—When conducting research, CBO staff can experience tension between provision of client services and implementation of research activities. Coordinating with research partners ahead of time can help the CBO identify the best ways to avoid overburdening clients with research-related activities. Maintaining the rigorous study designs implemented by research institutions while allowing for the standard provision of services can be challenging. However, academic and community partners involved in CBPR increasingly acknowledge the uncontrolled factors that come with conducting studies in a community setting.¹⁴ Partners are recognizing the need to allow for flexibility in the research plan. For example, in a multi-site study funded by the Patient-Centered Outcomes Research Institute (PCORI), the principal investigator at Georgetown University (KG) deliberately included broad participant eligibility guidelines. The study aims to evaluate the impact of a NV mental health intervention on Latina breast cancer survivors' and their caregivers' quality of life. To facilitate greater participation among partnering CBOs, the principal investigator also recognized that each site has different types of interventionists on staff (e.g., some who are clinically trained and licensed and some who are peers). These actions made it easier for CBOs, including NV, to participate in the study, recognizing varied organizational resources/capacity. These decisions exemplify how CBOs and researchers can reach reasonable compromises that will not undermine the integrity of the research results nor the quality of client services.

- How will the design of the study and its procedures impact direct service provision?
- What adaptations to the study design or eligibility criteria can be made to better facilitate CBO participation while maintaining quality of client services?

4. Gradually incorporate and modify evaluation methods. (Capacity, Operations)—Many CBOs may find it difficult to prioritize evaluation, particularly when their focus is on direct service provision. With limited staff resources and evaluation infrastructure, the prospect of planning data collection may initially seem to be superfluous and time-consuming. However, in the case of NV, the CBO's founders initiated the push for evaluation, recognizing the importance of empirically demonstrating the impact of service provision to establish credibility (discussed explicitly in the following tip).

Collecting of information about clients is vitally important for a CBO long before its participation in CBPR. Typically, recording data is a part of standard service provision and/or funding requirements. For NV, initial records included basic demographic client information, the number and types of services provided, barriers in access to care, and

clients' current health care practices. Later, satisfaction questionnaires were utilized for service improvement. Subsequently, NV approached academic partners with the goal of addressing identified gaps in the literature on programs for Latinas with cancer and cultural factors to consider when providing services to this group. These initial partnerships yielded studies that involved qualitative methods (i.e. focus groups, key informant interviews) resulting in peer-reviewed publications and presentations at research conferences.^{6, 8, 9, 13} After years of incorporating and enhancing evaluation and data collection methods, NV transitioned from record keeping using spreadsheets to more systematic collection using a database. The database was designed to collect both qualitative and quantitative data that had been introduced to NV through research partnerships (Further description of data collection infrastructure in Tip 6). The evolution of NV's evaluation provided greater understanding of client characteristics and the impact of programs on outcomes important to the organization (e.g., quality of life of cancer survivors). NV was, thus, better equipped to participate in CBPR.

- What type of information is currently being collected and what methods are used for collection?
- If not currently collected, what are feasible means of collecting desired data, given limited resources and staff time?

5. Demonstrate use of best practices for organizational credibility. (Capacity)

—Strategies CBOs can use to demonstrate organizational credibility include listening to and documenting client and community needs related to service provision. For example, NV has used satisfaction questionnaires, focus groups, and individual patient interviews to evaluate if the services being offered were meeting the needs and expectations of NV's clients. A CBO can then adapt services and programs based on this information. In addition, CBOs can turn to the research literature to understand best practices, and to identify programs that have empirical evidence supporting their efficacy. In order to review the literature and identify best practices, a CBO may search online for journals and scholarly articles (e.g., PubMed) that relate to the services it provides. For staff members of a CBO that are unfamiliar with how to conduct literature searches, local public or academic libraries may offer training classes. CBOs can then begin to implement existing methods or models identified in the literature, making appropriate adaptations for cultural competence or other relevant considerations. These adaptations can be evaluated in the future and shared with the research community to demonstrate success in new contexts. One emerging example of this comes from NV's partnership with the Catholic University of America that sought to evaluate NV's impact on Latina breast cancer survivors' self-efficacy, quality of life, and distress. Research staff noted unexpected self-efficacy results. They surmised that the instrument used to capture this construct, which had been translated from English to Spanish, did not sufficiently reflect the cultural differences of their population. The research team then indicated an interest in the cultural adaptation and evaluation of the instrument in a future study.¹³

- What information from the client population would improve the organization's services?

- What are feasible means of collecting, compiling, and recording these findings?
- What are the best practices in the literature that may help shape the CBO's services? If there are gaps in the literature about best practices specific to the CBO's target population, how could existing methods, models or theories be adapted?

6. Adapt data collection methods. (Operations)—The more involved and detailed evaluation and research becomes, the more important it is to have organizational infrastructure such as standardized data gathering tools, research assistants, and a research manager. After basic data collection methods have been incorporated into the CBO's infrastructure, it may become necessary to use a database software program that will facilitate more accurate and complex record keeping. NV found that potential academic partners were consistently looking for information on the number of clients served and basic client demographics in order to consider partnerships. Therefore, in 2009, NV made the switch from paper case management forms and Excel reporting to an online case management and reporting system called Efforts to Outcomes.

- How efficient are current data collection methods? Consider staff time, logistical or technological investments, and the time needed to generate reports.
- What are possible means of improving data collection methods and what corresponding resources are needed to make those changes?

7. Plan integration of appropriate data collection and training into staff workflow. (Goodness of Fit, Operations)—Data collection can bring challenges to CBOs both in terms of planning for and contributing to CBPR. First, staff time and resources may be scarce. NV's staff members often reported being overwhelmed with day-to-day duties and responsibilities. A careful balance must be observed between service provision and data collection so staff members are not overburdened with additional evaluation-related tasks.

While staff members have their primary service responsibilities, their participation in the development of research and evaluation is critical for successful CBPR. Educating all staff on the importance of data collection, research, and evaluation is an important foundation. Refresher trainings also help to ensure the continued quality of data collection. The next action is to hire a full- or part-time research and evaluation manager to assist staff and coordinate these types of activities. Interns and volunteers may also serve as resources for data collection. Recruited through universities' career centers and fairs, interns can help implement evaluation of programs. This evaluation can be included in progress reports requested by grant-making foundations and may also provide preliminary data for new grants and study collaborations. These opportunities may also provide interns with the opportunity to co-author an abstract or peer-reviewed article. In addition, hosting interns will cultivate a cadre of future researchers who are culturally and linguistically attuned to working with at-risk populations and with CBOs.

Alternately, not all data need to be recorded by CBO staff. In some cases, using staff from partnering academic institutions to record data may be a more logical option. In the PCORI study, the principal investigator (KG) elected to have research staff at her university conduct study assessments of outcomes to promote consistency across multiple sites and separate out the provision of services from the collection of data. In this project, CBO staff will record study participation, intervention process data, and assist with tracking of research participants.

Understanding the power of data was an important lesson for the staff members at NV, who were already overwhelmed with work. However, changes to the data collection system and careful planning of staff and intern workflow increased the CBO's capacity for systematic data collection and CBPR involvement.

- What are the current strengths and limitations to staff participation if new data collection methods were introduced?
- What resources exist to incorporate new data collection? Consider staff time, technological resources, and local students and volunteer organizations.
- What up-front and on-going staff training is needed?

8. Make predictions on how the target population's health behavior and culture may impact study implementation. (Goodness of Fit)—When conducting research in a community setting, it may be difficult to maintain the prolonged, quality contact with participants needed for research due to unforeseen events and transient populations. Ways to overcome these obstacles include frequent contact and database updates, as well as establishing familiarity and trust with participants over time. Having staff that share similar cultural backgrounds or similar health experiences with participants also helps achieve the trust needed for continued involvement. Because of their awareness of the strong cultural stigma associated with mental health, NV leadership recommended the use of the term “charlas,” or workshops, instead of mental health or therapy when promoting a study intervention. NV staff also regularly explained the important role the participants had in each study, creating stronger bonds that reduced the number of participants lost during follow up.

- Considering the community's general cultural values and health behaviors, what challenges might a CBO encounter when implementing a given study?
- What actions can CBOs and academic partners take to address these challenges?

9. Identify potential academic partners and research funding opportunities. (Goodness of Fit, Capacity, Operations)—Three means of increasing a CBO's awareness of potential partners and funding include: attending relevant conferences; observing other collaborative approaches and research methods; and sharing study findings to increase the credibility and exposure of the CBO's capacity for research. One such

conference relevant to CBPR is the Community-Campus Partnerships for Health (CCPH) annual conference. Additionally, there are topic-specific conferences that facilitate potential networking with researchers in the CBO's area of work. Through engaging in these activities, CBOs will develop an awareness of existing research opportunities and potential partners. A CBO's continued search for and involvement in research-oriented organizations can bolster future research opportunities. When identifying research funding, CBOs can look to traditional funding mechanisms, like the National Institutes of Health, and to foundations that support research. In the case of NV, a long-time funder of the organization's programs provided support for the collaborative study with the Catholic University of America¹³ and a study of quality of life.⁸ Likewise, some funding agencies focus on patient-reported outcomes that may be a good fit for CBO participation (e.g., PCORI).

- What conferences focus on topics relating to CBO's core services or CBPR?
- Which current organizational funders have previously supported research/evaluation projects or expressed an interest in doing so?
- What other public or private funding may align with a CBPR study?

10. Establish and maintain relationships with researchers interested in community health and the organization's area of focus. (Goodness of Fit, Capacity, Operations)—With the greater awareness of potential collaborators and funding mechanisms described in the previous tip, CBOs can take action in cultivating research partnerships. With knowledge of researchers that have previously conducted studies on topics that pertain to shared CBO interests, the organization can contact them directly to present the organization and discuss the potential for research collaboration. An organization can also connect with new investigators and resources through its network of funders and organizational partners.¹⁵

Maintenance of relationships with researchers requires regular contact and routine discussion of potential collaborations. Strengthening existing partnerships, even with no funds in place, and actively searching for new funding sources both enhance future funding opportunities. Presenting opportunities and ideas ought not be one-sided. For example, NV became aware of private research opportunities through meetings with long-time organizational funders. NV leadership consequently contacted partners at Georgetown University and George Washington Cancer Institute to discuss how these particular opportunities may be of mutual interest.

- How can the CBO leverage its network to connect with new investigators and resources?
- What current relationship maintenance is employed by the CBO, and how could it be improved?

SUMMARY

Through CBOs' focus on relevant questions and the real-world application of programs and interventions, community organizations possess a perspective valuable to research. To meet

the needs of a growing body of research that underscores the value of CBO engagement, it is imperative that CBOs develop the knowledge and tools needed for involvement in CBPR. Using NV as a case study of one CBO that became increasingly more involved in research, we have highlighted ten foundational tips CBOs need to apply in order to plan for or implement during CBPR. With an understanding of the actions necessary for CBPR engagement, CBOs will be better equipped to contribute to the research literature and ultimately improve services to and outcomes among the clients they serve.

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Figure 1.

Timeline of Nueva Vida's research contributions through CBPR

Note: Years indicate study implementation period

Table 1

Summary of Nueva Vida, Inc. Collaborative Studies

Study Title	Collaboration Partner	NV's role & sample size	Objective & Methodology	Publication
Latina Breast Cancer Survivors' Lived Experiences: Diagnosis, Treatment and Beyond.	Lydia Buki, Ph.D. Associate Professor, Department of Kinesiology and Community Health, University of Illinois at Urbana-Champaign	Co-PI 18 cancer survivors.	Latina breast cancer survivors not benefiting from advances in psychosocial interventions. Limited information about this population. This qualitative study examined the experiences of 18 immigrant Latina breast cancer survivors along the survivorship continuum, from diagnosis to long-term survivorship. (qualitative - focus groups)	Journal of Cultural Diversity and Ethnic Minority Psychology. 2008 Apr; 14(2): 163–7.
Latina a Latina: Developing a breast cancer decision support intervention.	Partnership: Sheppard, V. B, Figueiredo, M., Cañar, J., Goodman, M., Caicedo L., Kaufman, A., Norling, G., Mandelblatt, J., Latin American Cancer Research Coalition, Georgetown-Lombardi Comprehensive Cancer Center	Co-Author 3 survivor advocates, 17 Latinas in active treatment	Aims were to: (1) identify factors in Latinas' treatment decision making and (2) develop and pilot a decision support intervention. (formative – pilot intervention)	Journal of Psycho-oncology. 2008 Apr; 17(4): 383–91.
Quality of Life among immigrant Latina breast cancer survivors: realities of culture and enhancing cancer care.	M. Lopez-Class, M. Perret-Gentil, B Kresling, L Caicedo, J.s. Mandelblatt, K.D. Graves. Latin American Cancer Research Coalition, Georgetown-Lombardi Comprehensive Cancer Center	Co-author 24 study participants	This study examined social, cultural, and health care system factors that impact quality of life and survivorship experiences of Latina immigrant breast cancer survivors. (qualitative study – interviews, focus groups)	Journal of Cancer Education. 2011 Dec; 26(4): 724–33.
Costs and outcomes evaluation of patient navigation after abnormal cancer screening: evidence from the Patient Navigation Research Program	S. Patierno et al, George Washington University and the National Cancer Institute	NV was 1 of 7 sites in the DC area. 90 NV participants	1) Determine if navigation will be more effective than no navigation in decreasing the time from suspicious finding to diagnostic resolution and the time from diagnosis to treatment initiation. 2) Determine if navigation is the most cost-effective strategy in terms of costs per quality adjusted year of life saved. 3) Determine what factors mediate the intervention effects. (formative)	Journal of Cancer. 2014 Feb; 120(4): 570–8.
Assessing the Awareness of and Willingness to Participate in Cancer Clinical Trials among Immigrant Latinos.	S.F. Wallington, G. Luta, A.M. Noone, L. Caicedo, M. Lopez-Glass, V. Sheppard, C. Spencer, J. Mandelblatt	Consultant and Co-author No participants	There is a paucity of data on determinants of clinical trial participation in the growing and diverse US Latino population. We describe correlates of awareness of and willingness to participate in clinical trials among Central and South American Latinos using safety net clinics. (cross-sectional survey)	Journal of Community Health. 2012 Apr; 37(2): 335–43.
Impact of NV's Model on Self-Efficacy in Latinas with Breast Cancer	Karlynn BrintzenhofeSzoc, PhD, MSW, OSW-C, James R. Zabora, ScD National Catholic School of Social Service of The Catholic University of America	90 NV study participants	To undertake an evaluation of NV's access and mental health programs to determine to what extent the NV model results in improved self-efficacy at the individual level; To examine the effect of NV's programs on levels of self-efficacy, psychological distress, and quality of life as primary outcomes. (quasi experimental time-series design)	Conference Presentation, San Antonio Breast Cancer Symposium. Submitted for publication to the Journal of Psycho-oncology. (Under review).

Study Title	Collaboration Partner	NV's role & sample size	Objective & Methodology	Publication
Through the Lens of Culture: Quality of Life Among Latina Breast Cancer Survivors	KD Graves, RE Jensen, J Cañar, M Perret-Gentil, KG Leventhal, F Gonzalez, L Caicedo, L Jandorf, & J Mandelblatt	Consultants and Co-authors; 14 NV study participants	To evaluate cultural, social and medical-contextual variables that influence quality of life in Latina breast cancer survivors (nationally-recruited cross-sectional survey)	Journal of Breast Cancer Research and Treatment. 2012 Nov; 136(2): 603–13.